HEALTH CARE TECHNOLOGIES AT HOME

ISSUES IN ORGANIZATION AND DELIVERY IN QUÉBEC

AGENCE D'ÉVALUATION DES TECHNOLOGIES
ET DES MODES D'INTERVENTION EN SANTÉ

Québec

Health Care Technology at Home

Issues in Organization and Delivery in Québec

Report prepared for AETMIS
by Pascale Lehoux and Susan Law
with the collaboration of Lucy Boothroyd

October 2004

Agence d'évaluation
des technologies
et des modes
d'intervention en santé
Québec

105-06612/

The content of this publication was written and produced by the *Agence d'évaluation des technologies et des modes d'intervention en santé* (AETMIS). Both the original report and its French version, titled *Les technologies de soins à domicile: enjeux de l'organisation et de la prestation des services au Québec* are available in PDF format on the AETMIS Web site.

Scientific review
Jean-Marie R. Lance, MSc (economics), Senior Scientific Advisor

Co-ordination and page layout
Jocelyne Guillot
Frédérique Stephan

Proofreading
Suzie Toutant

Bibliographic research
Micheline Paquin
Mathieu D'Amours

Collaboration
Lise-Ann Davignon

Communications and dissemination
Richard Lavoie, MA (communications)

For further information about this publication or any other AETMIS activity, please contact:

Agence d'évaluation des technologies et des modes d'intervention en santé
2021, Union Avenue, suite 1050
Montréal (Québec) H3A 2S9

Telephone: (514) 873-2563
Fax: (514) 873-1369
E-mail: aetmis@aetmis.gouv.qc.ca
Web site: www.aetmis.gouv.qc.ca

How to cite this document:

Agence d'évaluation des technologies et des modes d'intervention en santé (AETMIS). Health Care Technology at Home: Issues in Organization and Delivery in Québec. Report prepared by Pascale Lehoux and Susan Law with the collaboration of Lucy Boothroyd. (AETMIS 04-06). Montréal: AETMIS, 2004, xiv-102 p.

Legal deposit
Bibliothèque nationale du Québec, 2004
National Library of Canada, 2004
ISBN 2-550-43249-5 (French edition ISBN 2-550-43248-7)

© Gouvernement du Québec, 2004.

This report may be reproduced in whole or in part provided that the source is cited.

MISSION

The mission of the *Agence d'évaluation des technologies et des modes d'intervention en santé* (AETMIS) is to contribute to improving the Québec health-care system and to participate in the implementation of the Québec government's scientific policy. To accomplish this, the Agency advises and supports the Minister of Health and Social Services as well as the decision-makers in the health-care system, in matters concerning the assessment of health services and technologies. The Agency makes recommendations based on scientific reports assessing the introduction, diffusion and use of health technologies, including technical aids for disabled persons, as well as the modes of providing and organizing services. The assessments take into account many factors, such as efficacy, safety and efficiency, as well as ethical, social, organizational and economic implications.

EXECUTIVE

Dr. Luc Deschênes
Cancer surgeon, President and Chief Executive Officer of AETMIS, Montréal, and Chairman, Conseil médical du Québec, Québec

Dr. Véronique Déry
Public Health Physician, Chief Executive Officer and Scientific Director

Jean-Marie R. Lance
Economist, Senior Scientific Advisor

Dr. Alicia Framarin
Physician, Scientific Advisor

BOARD OF DIRECTORS

Dr. Jeffrey Barkun
Associate Professor, Department of Surgery, Faculty of Medicine, McGill University, and Surgeon, Royal Victoria Hospital (MUHC), Montréal

Dr. Marie-Dominique Beaulieu
Family Physician, Holder of the Dr. Sadok Besrour Chair in Family Medicine, CHUM, and Researcher, Unité de recherche évaluative, Hôpital Notre-Dame (CHUM), Montréal

Dr. Suzanne Claveau
Specialist in microbiology and infectious diseases, Hôtel-Dieu de Québec (CHUQ), Québec

Roger Jacob
Biomedical Engineer, Coordinator, Services des immobilisations, Agence de développement de réseaux locaux de services de santé et de services sociaux de Montréal, Montréal

Denise Leclerc
Pharmacist, Board Member of the Institut universitaire de gériatrie de Montréal, Montréal

Louise Montreuil
Assistant Executive Director, Direction générale de la coordination ministérielle des relations avec le réseau, ministère de la Santé et des Services sociaux, Québec

Dr. Jean-Marie Moutquin
Obstetrician/Gynecologist, Scientific Director, Centre de recherche, CHUS, Sherbrooke

Dr. Réginald Nadeau
Cardiologist, Hôpital du Sacré-Cœur, Montréal, Board Member of the Conseil du médicament du Québec

Guy Rocher
Sociologist, Professor, Département de sociologie, and Researcher, Centre de recherche en droit public, Université de Montréal, Montréal

Lee Soderstrom
Economist, Professor, Department of Economics, McGill University, Montréal

FOREWORD

Complex forms of clinical treatments administered at home have begun to emerge, such as intravenous therapy, artificial life support, assisted ventilation, cancer chemotherapy, and palliative care. This homeward shift of specialized care previously provided only in hospitals is leading to the creation of a new model of care, of which advanced technologies are a ubiquitous component. However, these changes are raising many organizational issues that one should better define before devising measures fostering the development of such services in Québec.

Such is the chief objective of this *Agence d'évaluation des technologies et des modes d'intervention en santé* (AETMIS) report. The report does not stem from a formal assessment request from policymakers in the health-care and social services system but was, instead, initiated in the wake of numerous discussions on the shift toward ambulatory care and the role that technology might play in such care.

Since the assessment of this new intervention modality is necessarily context-based, it first describes the main problems attendant upon the evolution of home-based care in Canada. We first note the weak interface between community-based home care and hospital-based home care programs. In addition to leading to increased responsibility being delegated to patients and caregivers, the introduction of specialized equipment into the home setting poses a number of risks. Lastly, despite the lack of cost-effectiveness data on home care services, they continue to be implemented.

The report then examines the prevalence and patterns of home use of certain advanced technologies by Québec's local community health centres (CLSCs) before the new local health and social services networks were established, and highlights the potential obstacles to and the opportunities for expanding the range of specialized home care. To broaden the discussion, this is followed by a synopsis, based on a review of the international scientific literature, of the organizational, social, ethical and legal aspects of specialized home care. Lastly, we examine how these aspects could be taken into account when providing and evaluating home care services in the specific context of Québec health-care reform.

The assessment thus brings out four main messages, around which are formulated recommendations aimed at better coordination of specialized home services, increased patient and caregiver support, a more critical look at the medicalization of the home, and the need to perform cost-effectiveness studies of these services.

In submitting this report, AETMIS hopes to promote delivery of home care that is satisfactory to patients and their families and effective from a clinical and organizational standpoint.

Dr. Luc Deschênes
Chairman and Chief Executive Officer

ACKNOWLEDGEMENTS

This report was prepared at the request of the *Agence d'évaluation des technologies et des modes d'intervention en santé* (AETMIS) by Pascale Lehoux, PhD, Associate Professor, Health Management Department, and Researcher, *Groupe de recherche interdisciplinaire en santé* (*GRIS*), *Université de Montréal* and AETMIS, and Susan Law, MHSc, Consultant Researcher, AETMIS, with the collaboration of Lucy Boothroyd, MSc, Consultant Researcher, AETMIS.

The authors would like to thank the following individuals for their contribution to this report in providing useful information and/or facilitating access to documents or data related to the use of technology in home care in Québec and elsewhere:

Liliane Bédard, *déléguée à la protection des usagers, Bureau du protecteur des usagers*

Gisèle Bélanger, Head Nurse, Intensive Ambulatory Care Services, Montreal Children's Hospital (MUHC), Montreal, Québec

Carole Charland, Research Assistant, *GRIS, Université de Montréal*, Montreal, Québec (at the time of the study)

Pierre Deschamps, Professor, Faculty of Law, McGill University, Montreal, Québec

Geoffrey Dougherty, M.D., Director, Intensive Ambulatory Care Services, Montreal Children's Hospital (MUHC), Montreal, Québec

Micheline Paquin, Library Technician, AETMIS

Marc-André St-Pierre, Economist, *Service de l'analyse statistique, Direction des indicateurs de résultats et information statistique (SIFO), Direction générale de la planification, Ministère de la Santé et des Services sociaux*

Pierre Vincent, Librarian, AETMIS

In addition, the authors would particularly like to thank the external reviewers who provided extremely helpful comments and further information to be incorporated into the final version of the report:

Hervé Anctil, *conseiller en planification, Ministère de la Santé et des Service sociaux*

Malcolm Anderson, PhD, Research Coordinator, Department of Rehabilitation, Queen's University, Kingston, Ontario

Danielle D'Amour, PhD, Assistant Professor, *Faculté des sciences infirmières, Université de Montréal*, Montreal, Québec

Mireille Dumont-Lemasson, *conseillère-cadre, Association des CLSC et des CHSLD du Québec*

Margaret Edwards, Project Manager, King's Fund, United Kingdom

Terry Kaufman, M.D., Chief Executive Officer, CLSC Notre-Dame-de-Grâce/Montreal-West, Montreal, Québec

Any criticisms or errors remain the responsibility of the authors.

CONFLICT OF INTEREST

None declared.

EXECUTIVE SUMMARY

INTRODUCTION

Most industrialized countries have initiated health care system reforms that are aiming to increase the number and scope of health services delivered on an ambulatory basis and at the patient's home. In Québec, this shift is called the *"virage ambulatoire"*. Traditional home healthcare services include case management, nursing, personal care, home support (or homemaking), occupational and physical therapies, social work counseling, nutrition counseling, and respiratory therapy [MacAdam, 2000]. More complex forms of clinical treatments at home are emerging, such as IV therapy, life support/ventilator assistance systems, cancer therapy, palliative care, and services for persons with AIDS or Alzheimer's disease [CIHI, 2003a]. This report is mainly concerned with these latter forms of interventions, i.e. high-tech home care. Technology, we argue, cannot simply be seen as one of several factors driving change in home care, but should be viewed as a pervasive component of a new model of care. The aim of this report is to identify the organizational issues associated with an increased use of health care technology at home and provide recommendations regarding the development of such services in Québec.

This report is organized in six parts. First, we present the rationale for this investigation and describe the methods and data sources. Second, we summarize the features of home health care service developments in Canada and present four problems raised by the increased use of technology at home. Third, we describe in greater detail the prevalence and patterns of the use of technology in home care services as provided by Québec local community health centres (CLSCs), and highlight potential barriers and opportunities in the expansion of such services. Fourth, we synthesize the organizational, social, ethical, and legal dimensions of technology-enhanced home care from a review of the international literature. Fifth, we analyze how such dimensions could be addressed in the delivery and evaluation of home care services, referring specifically to the Québec health care reform. Finally, in conclusion, we formulate recommendations and identify the actors whose decisions and actions might be influenced by this report.

CURRENT ISSUES IN BRINGING HOSPITAL TECHNOLOGY TO THE PATIENT'S HOME

Home care is included in the Canada Health Act as an Extended Health Care Service, but home care services are not regulated by the five principles of the Act. As a result, Canadians face varying eligibility, cost, quality, and access issues concerning home care services [MacAdam, 2000]. This explains, in part, why the Romanow Commission devoted a full chapter to home care, calling it the "next essential service" [Romanow, 2002, p. 171-188]. Globally, funding for home care has increased markedly over the past ten years. Home health care budgets nonetheless represent a small part of the total health budget in each province and territory. In 1999-2000, per capita public spending on home care in Québec was $69 (for a total of $508M) while the mean in Canada was $83 (www.hcerc.org). Each province/territory is responsible for making specific arrangements for the funding and delivery of home care, while the regional authorities have been increasingly important in the organization of services. Consumer involvement appears limited and inconsistent across provinces/territories and regions. Finally, even though several provincial/territorial programs have stressed that high-tech home care is an issue in their jurisdiction, no formal national policy to ensure safe, cost-effective, and patient-centered use of technology at home has been developed.

Four aspects of the developments and increased use of health care technology at home require immediate attention. The first of these is the **weak interface between community-based and**

specialized, hospital-based home care. Ninety percent of home health care services in Canada are provided by coordinated home care programs that are largely community-based, and administered by provincial health departments or local community/regional health boards [Larsen, 1996]. Most Canadian home care programs were established in the late 1970s or early 1980s. Yet during this same time period, drastic changes in diagnostic methods and in the delivery of treatments and rehabilitation services took place. In Québec, CLSCs have historically focused on illness prevention and health maintenance objectives for elderly clients living within their territory, aiming to preserve their clients' autonomy for as long as possible, delaying admission to a nursing home. In the mean time, hospitals have been actively developing ambulatory and home care services for patients with both acute and chronic diseases, where patient education and health promotion are of prime interest. Such hospital-based home care programs (e.g. parenteral nutrition) require ready access to medical expertise, well-trained nursing staff, multidisciplinary teams, and specialized equipment. Both CLSCs and hospitals are extending their traditional frontiers in terms of the types of patients receiving home care and the increasing sophistication of technology used at home. It is uncertain to what extent health care managers and care providers from both hospitals and community health centres are adapting to their new roles and to what extent they are coordinating their efforts to provide home care where patient care crosses institutional boundaries.

The second issue is the **increased responsibility delegated to patients and caregivers**. Despite the fact that home-based patients and their caregivers must learn and master more technical knowledge and skills in comparison to hospitalized patients, very few studies have investigated the knowledge and skills required to manipulate home care technologies appropriately and independently, and/or the user-friendliness of the technologies themselves. Furthermore, it is not clear who is ultimately accountable (clinically and legally) for the quality of care when specialized technology is being manipulated by patients and caregivers rather than professional care providers. Some technologies impose considerable burden on patients and their families. There may be significant variations amongst patients and caregivers in terms of their ability and/or willingness to learn and carry out clinical/technical tasks on a routine basis.

Thirdly, the **risks associated with home environments** are important. There are both practical and philosophical implications of the increased use of technology in a patient's home. It is often taken for granted that most "typical houses" would be suitable for the delivery of home care. Nonetheless, critical observers have pointed out that the homes of chronic care patients become "small hospitals", due to the use of specialized equipment and drugs and the need for a sterile environment and storage room. This change in the context of use may not be simply a matter of increased hygiene, adaptation of physical design, or appropriate supervision. It may involve more complex dynamics or implications for patients/families, such as risk-taking, and impact on psychological well-being, family relationships, or social networks.

The fourth aspect concerns the **implementation of home care services despite the lack of evidence about cost-effectiveness.** Hospital care services are generally very costly; it is thus often assumed intuitively that home care services are of equal or greater effectiveness at less cost. Some home care interventions have indeed been shown to be more cost-effective than hospital care, but the opposite has also been observed. Private and public costs—as well as indirect costs—have often not been assessed consistently. Overall, there is a lack of convincing evidence in the literature, and clinicians, as well as policy-makers, need to consider carefully the implications of proposals to substitute or complement traditional hospital care with home care services.

TECHNOLOGY AT HOME IN QUÉBEC

A study was conducted in 1999-2001 by the first author of this report (PL) and her colleagues at *Université de Montréal*. The aim of the research was to identify the organizational, technical, and human factors influencing the use of certain technologies at home by CLSCs. A mail-back survey was sent to CLSCs; the response rate was close to 70%. Almost all responding CLSCs had been involved in the provision of home IV therapy. The two most common modes of IV delivery were gravity (81.3% of CLSCs) and programmable pumps (97.9%), whereas the mechanical delivery system was used less frequently (58.9%). Oxygen therapy was the second most frequent home care service provided by CLSCs (with fixed concentrators: 83.5% of CLSCs). The provision of services related to parenteral nutrition was limited but still significant (26.6%). A large proportion of CLSCs (78.1%) indicated that they had been involved in the delivery of peritoneal dialysis care. A majority of CLSCs had been involved in the provision of anticoagulant therapy services (87.9%), while a third (35.6%) had been involved in the delivery of IV chemotherapy Despite the abundant literature underscoring the rapid growth of home telecare, the use of various information technology-based home monitoring services was infrequent.

Historically, CLSCs have been responsible for home care and other primary care services. The execution of their mandate has always been tightly linked to community approaches, emphasizing preventive services and educational interventions that aim to respond to local needs. With the *"virage ambulatoire"*, their mandate appears to shift towards post-acute, more specialized care. The provision of home IV therapy is an archetype of such a shift: the explicit goal is to shorten hospital length of stay, using CLSC staff to provide and monitor therapy at the patient's home. However, one may question whether the CLSC organizational design and professional expertise could be better supported to accommodate the *"virage ambulatoire"*. The advent of the *centres de santé et de services sociaux* and the *réseaux locaux de services*, resulting from CLSCs merging between them or with hospitals, might contribute to answer to this need.

ISSUES IN ORGANIZATION AND DELIVERY

Introducing sophisticated technologies into the home setting has created new types of patients, new treatment possibilities, new roles and responsibilities for providers and caregivers, new ethical dilemmas, and new areas of accountability. Part 4 of the report is an attempt to clarify and summarize issues that are often entangled both in the literature and in practice. Organizational dimensions of technology-enhanced home care are intimately linked to the characteristics of the home care delivery model, and to the particular needs of patients in terms of care, technology, and support. Social dimensions of the use of technology at home refer to the capacity of the patients and their relatives to maintain satisfying relationships, to engage in leisure activities, to raise a family, to carry out social roles, to be employed and earn an income, and to live without discrimination. Several factors suggest that issues of legal liability in home care will increase [Kapp, 1995a]: home care is becoming increasingly high-tech; patients are being discharged "quicker and sicker"; and the coordination of care provided by various professionals is becoming more complex (making it increasingly difficult to control legal risks).

Thus, a complete home care policy should include organizational incentives that promote collaboration and trusting relationships between organizations, between service providers, and between public health organizations and the informal/voluntary sector. A home care policy should also recognize the major role women play in informal care giving and sustain real choice by allowing them, for example, either to provide care without paying the indirect opportunity costs (in terms of career opportunities, health, etc.) or to choose not to play such a role. Finally, home care policy should be attuned to the ethical and legal considerations associated with high-tech (and possibly high-risk) interventions.

DISCUSSION

Part 5 of the report aims to bring together the issues raised in the previous parts. Recommendations are formulated around four central messages.

Recommendation 1: Establish innovative organizational mechanisms that support the delivery of coordinated home care. As shown throughout this report, technology-enhanced home care is not a straightforward solution to a health system shift such as the *"virage ambulatoire"*. The integration of technology into existing models of care gives a prominent role to community-based and primary care organizations. The survey on the use of technology in CLSCs revealed that their involvement in specialized home care was uneven across Québec, and was often unknown to specialized hospital home care teams [Law and Lehoux, 2001]. The number of patients they visit, as well as the ade quacy of the information and training available to CLSC staff, raises issues on the quality of service provided.. Although relationships between CLSCs and hospitals were perceived as generally positive, important organizational limitations inherent to the current model of home care delivery have been reached: good relationships alone are not sufficient, and the effective coordination of services requires inter-organizational communication.

Recommendation 2: Increase the level of support for patients and caregivers. The contribution of caregivers to home care "has been by default, and not by design" [Parent and Anderson, 2000, p. 50]. For several observers, the benefits of home care outweigh the risks and liabilities, which can in turn be minimized by addressing the family's needs [Schachter and Holland, 1995]. To do so, care providers need to be trained and rewarded in a way that recognizes the importance of training, supporting, and supervising the patients' and caregivers' learning. Standards for supervision and the periodic verification of provider competence must be established. Nurses need to supplement their knowledge of nursing interventions with further training in ethics, health law, and technology. This new generation of nurses should also be aware of the means by which patients' needs and preferences can be elicited, given that appropriate and acceptable services can best be developed by integrating users' views into decisions about health services.

Recommendation 3: Revisit the medicalization of home. It may be an opportune moment to pause and consider the rationale for the rapid development of technology-enhanced home care. Kaye [1995, p. 3] expresses concerns about this hastened development: "the fact that home care exists in so many shapes and forms leads to questions about the capacity of such providers to deliver home care services in a consistent manner reflecting high levels of effectiveness and efficiency. This kind of concern should remain at the root of home care development. Specialized equipment should be designed in order to fill existing gaps in our ability to respond to health needs. In addition, the effectiveness of home care is inherently linked to the social and clinical criteria by which patients are selected. This implies that some patients will be excluded from home care services, a situation that calls for particular attention.

Recommendation 4: Support high quality research into the cost-effectiveness of home care. More research should be conducted on home care services, especially to investigate the cost-effectiveness of specific technology-enhanced services. However, supporting the production of research is far from enough. The results of such studies should be widely disseminated and discussed with key decision-makers and clinicians. Home care is not a static, homogeneous category of interventions. Its impact on health and social service costs depends on the intervention, on the particular health condition, and on the way services are provided and organized [Soderstrom et al., 1999]. Given outstanding challenges in the methodology and controversy in the interpretation of the results of cost-effectiveness studies, it seems important to create specific forums in which the cost-effectiveness of particular home care programs would be clarified and debated amongst practitioners, researchers, and policy-makers. Clinicians, hospital-based home care program managers, CLSC home care program managers, researchers, and planners from the *Ministère de* *la Santé et des Services sociaux* should attend such forums with the aim of reaching some form of consensus with respect to what type of home care interventions should be supported in Québec.

CONCLUSION

Current challenges in the organization and delivery of home care call for immediate policy actions. Sophisticated technology is changing the nature of health systems across industrialized countries, and one of its most significant developments is the use of complex equipment in the patient's home. The use of such equipment often requires the clinical and technical expertise of secondary and tertiary level care providers, as well as a keen understanding of home care patients' needs—an expertise that CLSC home care program staff have developed for particular clientele over the last two decades in Québec. One critical challenge, for the next decade, will be to bring these two types of expertise together in order to provide specialized home care that remains meaningful for the patients and their relatives, while being effective from clinical and organizational perspectives. In this endeavour, coordination among individual care providers and among health organizations is key, as is building the technical and clinical competence of providers, patients, and caregivers. Each of our four recommendations addresses a particular facet of the 'home care problem'. While a global vision of home care should help structure the future of this service in Québec, regional leadership is required to support and implement organizational incentives that will enable effective coordination between hospitals and CLSCs or the *réseaux locaux de services* in which they are now integrated.

TABLE OF CONTENTS

MISSION iii

FOREWORD v

ACKNOWLEDGEMENTS vi

EXECUTIVE SUMMARY vii

1 INTRODUCTION 1

- 1.1 Home care delivery models: Newly established and yet still adequate? 1
- 1.2 A crucial component in health care reforms: Technology at home 1
- 1.3 Objectives of the report and general approach 2
- 1.4 Why an AETMIS report on technology-enhanced home care? 3
- 1.5 Outline of the report 4
- 1.6 Methods and data sources 4

2 BRINGING HOSPITAL TECHNOLOGY TO THE PATIENT'S HOME 6

- 2.1 The rapid growth of home care: Could technology be more than a simple factor? 6
  - 2.1.1 Increased funding 6
  - 2.1.2 Market incentives behind innovation 7
  - 2.1.3 Policy-making environment 8
  - 2.1.4 Social environment 9
- 2.2 Regulation of home care: general definitions 9
- 2.3 Funding and utilization of home care in Canada 10
- 2.4 Similarities and differences across Canada 14
- 2.5 Technology in home care: Some examples 15
- 2.6 Technology and functions of home care 18
- 2.7 Definition of the problem addressed in this report 18
  - 2.7.1 Problem 1: The weak interface between community-based and specialized hospital-based home care 19
  - 2.7.2 Problem 2: Increased responsibility delegated to patients and caregivers 19
  - 2.7.3 Problem 3: Medicalization of the home 20
  - 2.7.4 Problem 4: Implementation of programs despite the lack of evidence about their cost-effectiveness 21
- 2.8 Conceptual framework 21

3 TECHNOLOGY USED AT HOME IN QUÉBEC CLSCS 23

- 3.1 Home care in Québec 23
- 3.2 A survey on technology use by Québec CLSCs 24
- 3.3 To what extent are technologies used by CLSCs? 24
- 3.4 Barriers to the integration of technology in CLSCs home care programs 27
- 3.5 Organizational issues and relationships with hospitals 29
- 3.6 Discussion 31

4 ISSUES IN ORGANIZATION AND DELIVERY 35
  4.1 Organizational dimensions 35
    4.1.1 Cost-effectiveness 35
    4.1.2 Integrated health care delivery models 37
    4.1.3 Physician involvement in home care 39
    4.1.4 Working in home care 39
    4.1.5 Provider-patient communication 40
    4.1.6 Home adaptations and equipment design 40
  4.2 Social dimensions 41
    4.2.1 Impact on caregivers 41
    4.2.2 Who are the caregivers? 42
    4.2.3 Measuring and addressing caregiver burden 43
    4.2.4 Situations where home care alters social relations 44
  4.3 Ethical issues 44
    4.3.1 General definitions 45
    4.3.2 Comfort vs. life-sustaining treatments 46
    4.3.3 Capacity issues 46
  4.4 Legal issues 47
    4.4.1 Overview: Five legal aspects 47
    4.4.2 Caregivers' legal responsibilities 48
    4.4.3 Providers' areas of accountability 49
    4.4.4 Competence of care providers as a legal requirement 49
    4.4.5 End of life considerations 50
    4.4.6 Record keeping 50
    4.4.7 Equipment liability 51
    4.4.8 Risk management 51
  4.5 Steps forward 52
5 DISCUSSION 53
  5.1 Assumptions about the purpose of home care 53
  5.2 Can the Québec home care delivery system integrate technology-enhanced home care services? 54
  5.3 Addressing the "technology at home problem" in Québec 55
    5.3.1 Recommendation 1: Establish innovative organizational mechanisms that support the delivery of coordinated home care 55
    5.3.2 Recommendation 2: Increase the level of support for patients and caregivers 56
    5.3.3 Recommendation 3: Revisit the medicalization of home 58
    5.3.4 Recommendation 4: Support high-quality research into the cost-effectiveness of home care 59
6 CONCLUSION 60
  6.1 Whose decisions and actions should be influenced by this report and how? 60
APPENDIX: REFERENCES GROUPED BY TOPICS 62
REFERENCES 82

LIST OF BOXES, FIGURES AND TABLES

Box 1. The impact of nine policy issues on home care 8
Box 2. Infusion therapies: venous access and catheters 16
Box 3. Key findings from the CLSC survey 32
Box 4. Guiding points to minimize risks with respect to administration of drugs 51
Box 5. Key points for a Québec home care policy 52
Box 6. Whose decisions and actions should be influenced by this report? 61

Figure 1. Per capita expenditures for home care ($CDN, 1999-2000) 14
Figure 2. Problematic issues in technology-enhanced home care 21
Figure 3. First year of introduction of thechnologies by CLSCs 27
Figure 4. Proportion of CLSCs providing technology-enhanced home care services 27
Figure 5. Perceived barriers to the integration of technology-enhanced home care 28
Figure 6. Topics discussed and frequency of formal agreements 31

Table 1. Funding and issues in home care across Canada 12
Table 2. Utilization of selected technologies by CLSCs 25
Table 3. Number of CLSC patients, 1998-1999 26
Table 4. Perceived trends in the number of patients since 1996 26
Table 5. Percentage of CLSCs indicating patients had to pay for these items 29
Table 6. Sources of information used by CLSCs (%) 29
Table 7. Sources of training for CLSC staff (%) 30
Table 8. Aspects defining the relationships between CLSCs and hospitals (% endorsed) 31
Table 9. Technology-enhanced services/equipment provided by home health care agencies (N=140) 33
Table 10. Ethical and legal issues faced by American home health care agencies 47
Table A-11. Governmental publications (Canada, Province of Québec, USA) 63
Table A-12. Health organizations publications 65
Table A-13. HTA agencies and research groups publications 66
Table A-14. Clinical dimensions (nursing care, effectiveness, safety, etc.) 67
Table A-15. Organizational dimensions (including patient education) 69
Table A-16. Social dimensions, with special emphasis on user's perspective 74
Table A-17. Ethical and/or legal dimensions 76
Table A-18. Medical equipment and R&D issues 78
Table A-19. Other (costs, methodological aspects) 80

1 INTRODUCTION

1.1 HOME CARE DELIVERY MODELS: NEWLY ESTABLISHED AND YET STILL ADEQUATE?

Health Canada defines home care as: "an array of services which enables clients, incapacitated in whole or in part, to live at home, often with the effect of preventing, delaying, or substituting for long-term care or acute care alternatives" [Dumont, Lemasson et al., 1999]. Home care typically includes professional services (case management, nursing, occupational and physical therapies, respiratory therapy, social work counseling, nutrition counseling, etc.), personal care (bathing, toileting, grooming), and other home support and homemaking services (meal preparation, cleaning, laundry) [Romanow, 2002, p. 173]. Community support services, such as adult day centres, transportation, home maintenance, and "meals-on-wheels", usually complement professional-clinical services by offering social support and activities to home-bound persons and those who have lost their autonomy. More complex forms of clinical treatments at home are emerging, such as IV therapy, life support/ventilator assistance systems, cancer therapy, palliative care, and services for persons with AIDS or Alzheimer's disease [CIHI, 2003a]. It is with these latter forms of interventions that this report is mainly concerned, i.e. high-tech home care (defined below). As MacAdam [2000, p. 20] recently emphasized, "the increasing use of technology in the home raises many policy questions that have yet to be addressed".

Most of the provincial/territorial home care programs were established in the late 1970s or early 1980s. In the 1990s, up to 90% of home care services in Canada were provided by coordinated home care programs (CHCPs) [Larsen,1996]. CHCPs are largely community-based, and administered by provincial health and social service departments or local community/regional health boards rather than non-profit voluntary agencies (which is more common in the United States, for instance). Home care services are typically delivered by home care program staff, by voluntary or not-for-profit agencies, or by both. The practice of contracting-out of services (with private agencies) appears to be growing.

Yet during this same time period, there have been drastic changes in diagnostic methods, as well as in the provision of clinical treatments and rehabilitation services. As we will argue further, technology cannot simply be seen as one of several factors driving change in home care, but should be viewed as a pervasive component of a new model of care. Our working hypothesis is that health care technology is destabilizing, in an important manner, the foundations of existing models of home care programs. The goal of this report is to identify the organizational issues associated with the increased use of health care technology at home and provide recommendations regarding the development of such services in Québec. In other words, what problems and issues might compromise or impede the appropriate use of technology in home care?

1.2 A CRUCIAL COMPONENT IN HEALTH CARE REFORMS: TECHNOLOGY AT HOME

Kaye and Davitt [1995b, p. 67] define technology-enhanced home care services—or high-tech home care—as "methods of diagnosis, treatment or rehabilitation which are embodied in or supported by specialized equipment." Agency providers of home health care often emphasize the complexity of interventions, or the fact that they require new or specialized skills on the part of the nurse or therapist (e.g., infusion therapy, respiratory support, dialysis, artificial nutrition and hydration, cardiac monitoring). "Smart house" designs (personal emergency response systems, self-instruction computers, robotics, etc.) are also seen as part of the technological systems available to support handicapped or elderly persons in their homes. Kaye and Davitt [1995b] thus classify high-tech home care in two categories: 1) medical services, treatment, and equipment; and 2) home adaptations and environmental designs.

Some may consider the use of the term 'high-tech' debatable. From a training and skills perspective, a particular intervention may be high-tech for some providers, but not for others. The frequency at which providers (clinicians and organizations) use an intervention is related to their level of confidence and skill. In addition, technology evolves over time and design improvements may increase its user-friendliness. Hence, an intervention may be considered high-tech only in certain contexts, and within certain time frames. In this report, we will use the terms 'technology-enhanced' or 'high-tech' home care to focus attention on the technological component of health care services currently delivered in patients' homes.

Since the mid-1980s, the increasing use, and sophistication, of technology at home has been an important component of most health system reforms across industrialized countries. Technological development has played an active role in the expansion of home care and continues to shape the services patients receive during and after shortened hospital stays [CIHI, 2002]. For instance, technology supports less invasive surgery that allows patients to be discharged earlier; improvements in equipment design results in portable and automatic devices that can be used on an outpatient basis; and, technologies usable by chronic patients themselves to maintain their independence are more readily available than 20 years ago. Even though health reforms are actively promoting technologies that foster the provision of ambulatory services, there are strong market incentives behind technological development as well. For instance, a growing elderly population provides a vast potential market for home emergency response systems as do increasing numbers of patients with chronic obstructive pulmonary diseases (COPD) for ambulatory oxygen support. Nonetheless, the potential health benefits that patients and Québec society may derive from all the technological advances and opportunities are not straightforward. Technological niches in the market do not necessarily overlap with population health needs, and an increased use of technology does not automatically imply better outcomes in terms of health and quality of life. This concern with the appropriate and cost-effective use of technology has premised the emergence of the field of health technology assessment in most industrialized countries.

1.3 OBJECTIVES OF THE REPORT AND GENERAL APPROACH

The main objectives of this report are to identify the issues raised by the increasing use of technology in home care, and to formulate recommendations that will help decision-makers and providers shape the future of home care delivery in Québec. This report is part of a series produced by AETMIS on technology at home. Whereas the others focus on individual technologies (e.g., parenteral nutrition, oxygen therapy, chemotherapy) examining efficacy, safety, and costs, this report takes a different yet complementary approach, in that it addresses more broadly the organization and delivery issues of technology-enhanced home care and their implications for policy, practice, and research in general. Data on the use of technology in Québec *CLSCs* (now integrated in the new *réseaux locaux de services*) home care programs is also presented. Together, the full series of reports aims to develop a detailed information/evidence basis for decision- and policy-making with respect to technology at home. Our premise is that an interdisciplinary integration of the available knowledge about this area is an essential starting point. In this way, we hope to contribute to the development, implementation, and maintenance of cost-effective, safe, desirable and user-friendly technology-based home care initiatives and policies in Québec.

In order to meet these objectives, two considerations were taken into account while developing this report. First, it had to be of interest to, and readable by, a wide and diversified audience. Physicians, nurses, biomedical engineers, managers, policy-makers, patients, and caregivers are considered potential decision-makers at different levels of the health system. Consequently, the report had to summarize (and simplify somewhat) several aspects of technologies used at home. As the preferred setting for the delivery of a significant proportion of health care is moving away from the hospital and infiltrating the intimate lives of people at home, the organizational, ethical, legal, and social implications of such a shift required study. These dimensions had to be dealt with concurrently in a single document for such a report to contribute to a comprehensive provincial policy for technology-based home care.

Second, perhaps more strikingly than with traditional hospital-based technology, the extent of user-friendliness of the equipment and devices intended for use in the patient's home may impinge on its clinical effectiveness. The user-friendliness of technology is defined by technical factors (resulting from design) and human factors (cognitive, physical, and mental abilities of users), which both affect the level of compliance of patients [Lehoux et al., 2001a]. There are in fact two groups of individuals responsible for the utilization of technology at home: 1) providers; 2) and patients and caregivers. The effectiveness of home care technologies depends on their appropriate use by lay persons (patients and caregivers) who have presumably little technical knowledge with respect to medical devices and health care. At the same time, the ability of professional providers (e.g. physicians, nurses, nutritionists, respiratory therapists, occupational therapists) to train lay persons—in terms of how these technologies work, how to use them safely and conveniently in daily living, how to detect functional/technical failures, or when to initiate emergency procedures—is certainly as important, in ensuring the appropriate use of technology, as the capacity for patients/caregivers to learn from experience. This implies that providers must have sufficient understanding of how patients and caregivers will resume regular routines and accommodate new "clinical" routines in their home environments after hospital discharge. Therefore, in this report we have attempted to reflect "both sides of the coin": that is, how both groups involved in providing technology-enhanced home care (professional and lay) perceive the user-friendliness of medical devices.

1.4 WHY AN AETMIS REPORT ON TECHNOLOGY-ENHANCED HOME CARE?

Two factors prompted the development of this report. First, several observers have stressed the need to examine more closely the appropriateness and implications of transferring the technological opportunities that have characterized the last few decades of the 20th century to the home environment [Parent and Anderson, 2001, 2000; Hollander et al., 2000; Anderson and Parent, 1999; Monk and Cox, 1995;]. Several key actors in the Québec health care system indicated this concern to AETMIS during the preparation of a report on priority topics for assessment [CETS, 1996], as well as in the course of informal and formal communication since then. Issues of clinical safety are natural considerations, but there are also ethical and social aspects that might directly affect the appropriateness of a home care policy in general. For instance, underprivileged patients may not have equitable access to home care, if they do not enjoy adequate social support, and/or if their financial resources are too limited to afford the indirect costs implied by home care (e.g. private aid, home adaptation, loss of income). Also, women in particular face consequences in a shift to home care, given that their role as "natural" caregivers is often assumed; their careers and health are often affected due to the time and effort devoted to care giving [Women's Association for Social Education and Action et al., 1998]. Thus, even though the Government of Québec promotes a policy that encourages technology-based home care, there is a need to identify the settings in which such a reform is most likely to prove beneficial for patients and society, and the conditions under which it could have negative implications.

Second, although a wealth of published studies on certain specific home care topics (e.g. effectiveness of IV therapy) can be identified, very few attempts have been made to synthesize the knowledge stemming from the non-clinical literature (e.g. social, scientific). As mentioned above, the use of medical technology in domestic environments implies a large set of interrelated issues. For instance, what are the clinical and social criteria by which certain patients are included or excluded from home care programs? What are the moral dilemmas stemming from the application of such criteria (e.g. do some programs perform well, in part, because only highly autonomous patients are enrolled)? What are the psychosocial implications of caregivers carrying out intimate care procedures, and sophisticated technical interventions (i.e. stress related to concern about the patient's injury or death or risks to their own health)? For example, can society ask an elderly woman to provide care to her spouse when he may need the services provided by an institution? The above questions provide some of the rationale for examining the diverse multidisciplinary perspectives in this report. Restricting the discussion to the clinical issues only would avoid these complex and value-laden questions. We believe that it is time to stimulate and broaden the debate about technology at home in Québec. Observing home-based technology from different perspectives should help decision-makers forge judgments about its overall appropriateness. In addition, the role of AETMIS as an arm's-length government agency is to examine, analyze, and synthesize the available evidence in order to clarify key issues from a provincial perspective, ensuring that individuals and organizations concerned with the provision of home care can use this synthesis in their decision-making processes.

1.5 OUTLINE OF THE REPORT

Our report is organized in six sections (excluding the Appendix). First, this introduction defines the problem, the methods, and data sources. Chapter 2 describes the main factors stimulating the growth of home care, the risks associated with increased use of technology, and a conceptual framework that should contribute to a broader understanding of the organization and use of such services. Chapter 3 describes and discusses the involvement of CLSCs in the use of specific technologies in Québec, as well as existing inter-organizational barriers and opportunities. Chapter 4 synthesizes the organizational, social, ethical, and legal aspects of using health care technologies at home. Chapter 5 presents a policy-oriented discussion of the principles that could guide the future development of home care in Québec. In the conclusion, we present practical recommendations and an overview of the potential influence this report could have on the evolution of home care in Québec. The papers, policy documents, and research reports consulted are summarized in the Appendix.

1.6 METHODS AND DATA SOURCES

This report is based on two main sources of information: 1) a broad review of the international literature; and 2) data from a mail-back survey sent to Québec CLSCs. With respect to the literature review, searches on PubMed (National Library of Medicine, including Medline and pre-Medline) were conducted using the following key words: "high-tech home care", "home care delivery models", "ethical issues", "legal issues", "social issues", and "organizational issues". The libraries of the main universities in Québec as well as the library of the *Ministère de la Santé et des Services sociaux* (1980-2002) were searched. Research reports published by health technology assessment agencies (on their Web sites) and university-based health services research groups were also retrieved. Relevant references were extracted from the consulted papers. More than 200 papers, book chapters, and monographs were gathered. Qualitative articles addressing the viewpoints of clinicians, care managers, patients, or caregivers received special attention. This report summarizes key observations within the literature that appeared consistently (as a form of consensus amongst the groups), that highlighted perspectives from "both sides of the coin", that were likely to respond to decision-makers' information needs, and that reported experiences relevant to the Canadian and Québec contexts.

Data describing technology use within Québec CLSCs were obtained via a mail-back survey sent to 140 CLSCs across Québec. This survey was part of a wider research project funded by the Canadian Institutes of Health Research [Lehoux et al., 1998]. This research aimed to document the organizational framework in which CLSCs integrate (or do not integrate) four technologies (oxygen therapy, dialysis, parenteral nutrition, and IV therapy), and the level of user-friendliness perceived by providers, patients, and caregivers. The survey was administered in February 2000. After three reminders (two by mail, one by telephone), the response rate was 69.3%. A detailed report is available through the secretariat of the *Groupe de recherche interdisciplinaire en santé* (GRIS), *Université de Montréal* [Lehoux et al., 2001a].

As per the production process adopted by AETMIS for all scientific reports, the above two sources of information were supplemented by exploratory interviews with clinicians and managers at the outset of the project, by formal expert advice gathered during an external review process (see acknowledgements), and by regular discussions with AETMIS researchers and members of the Board.

2 BRINGING HOSPITAL TECHNOLOGY TO THE PATIENT'S HOME

In this chapter, we discuss the factors propelling important changes in home care practices and policies. New technologies that are likely to affect home care in the near future are described with respect to their use in acute, chronic, or palliative care. Four aspects of an increased shift towards technology-enhanced home care require immediate attention in terms of policy, practice, and research: 1) the weak interface between community-based and specialized (hospital-based) home care; 2) the increased responsibility for health care delegated to patients and caregivers; 3) the risks associated with inappropriate or non-adapted home environments; and 4) the lack of evidence about the cost-effectiveness of home care. A framework is presented in order to structure the examination of issues that is central to this report.

2.1 THE RAPID GROWTH OF HOME CARE: COULD TECHNOLOGY BE MORE THAN A SIMPLE FACTOR?

Whereas the Hospital Insurance Act was one of the major social innovations that shaped the Canadian public institutions of the 1960s and 1970s, today the reverse movement is being observed: home care is one of the fastest developing areas in health care, shaping the provision of health care in the future. This partly explains why the Romanow Commission devoted a full chapter to home care, calling it the "next essential service" [Romanow, 2002, p. 171-188]. In Québec, home care is intimately linked to the *"virage ambulatoire"*. Interestingly, the *"virage ambulatoire"* cannot be considered a formal health system reform or a specific policy, as there is no single official government document describing its rationale, objectives, means, and expected outcomes. Despite this lack of a tangible frame of reference, the *"virage"* is real (and has negative connotations) for most Quebeckers. It is generally understood as the result of drastic cost-cutting efforts by the government (particularly during 1995-98) and of an unplanned reorganization of community and primary care bodies [Rodriguez and Frohlich, 1999]. The *"virage"* places particular emphasis on the increased provision of ambulatory and home care services, and on the enhanced role of primary care and community organizations. Similar shifts have been observed in most industrialized countries and are propelled by technological developments, new ways of treating diseases, increasing demand for health care services in patient-centered care and, of course, cost-containment incentives [CETS, 1996]. Alternatives to hospitalization (e.g. day surgery, ambulatory services) and institutionalization (e.g. psychosocial community-based interventions) are being actively sought by clinicians, planners, and administrators, and home care represents an important area for potential development.

According to Arras and Dubler [1995], "during the past ten years the high-tech home care industry has rapidly and relentlessly erased, for increasing numbers of families, the boundary between hospital and home, between the intensive care unit and the living room." Early forms of technology-enhanced home care focused on intravenous access/hydration and the delivery of parenteral nutrition. However, many new services and technologies have been recently introduced (examples are provided below). This growth can be described in terms of: 1) the level of funding; 2) the market incentives behind innovation; 3) the policy-making environment; and 4) the social environment.

2.1.1 Increased funding

The funding of home care in Canada is primarily secured through provincial governments (76%), private insurance and user fees (23%), and the federal government (1%) [Romanow, 2002, p. 174]. "Between 1980/81 and 2000/01, the average annual rate of growth for home care expenditures by provincial and territorial governments was 14% compared to 6.2% for hospitals and 7.1% for all provincial-territorial health expenditures" [Romanow, 2002, p. 175]. Although home care represents the fastest growing component of health expenditures, home care budgets represent only a small proportion of the total health budget in each province/territory (ranging between 2% in Nunavut and 10% in New Brunswick) [Romanow, 2002, p. 174]. The funding of home care in Canada has increased markedly over the past ten years, more than doubling since 1990 (from $1,028 million in 1990-91 to $2,096 million in 1997-98). From 1984-85 to 1995-96, the rate of increase varied from 669% in Ontario to 249% in Saskatchewan. The public home care expenditure of $2,096 million in 1997-98 represented an increase of 4.8% over the previous year [Health Canada, 1998a]. In Québec in 1999-2000, per capita spending for home care was $69 while the mean in Canada was $83. A total of $235M was spent on home care in 1990-1991, and $491M in 1999-2000, a growth of 109%, compared to a growth of 33% for the rest of social and health services [MSSS, 2001b, p. 67].

2.1.2 Market incentives behind innovation

Over the past two decades, emerging medical innovations in North America have been concentrated in tertiary care centres. As a consequence, "physicians are no longer seen as benevolent guardians; they have become the gatekeepers of this burgeoning technology" [Pousada, 1995, p. 107]. Support for patient autonomy and the more 'kindly' nature of the home, in comparison to institutional care, has coincided in the policy discourse with the financial realities of decreasing expenditures in health care. The pace at which specialized home care interventions have been introduced is impressive. In the USA, changes in federal reimbursement policies such as diagnosis-related groups (DRGs) and the Medicare Prospective Payment System have created financial incentives for hospitals to discharge patients earlier. The market for high-tech home care has been spectacular, with an overall rate of growth in revenues of 20 to 25 percent per year [Feder, 1991, cited in Arras and Dubler, 1995]. The US market for total parenteral nutrition (TPN) reached $622 million in 1991, and accounted for 21 percent of the total home infusion market [City of New York DCA, 1991 cited in Arras and Dubler, 1995]. The American IV therapy market alone went from $1 billion in 1987 to $3.3 billion in 1993 [Arno et al., 1995, p. 222]. In 1992, parenteral nutrition accounted for 20% of the reimbursement provided by Empire Blue Cross and Blue Shields for AIDS patients [Arno et al., 1995, p. 224]. Overall, there may be considerable financial pressure to expand in areas of new technology—with higher profit margin—in healthier patients, at the expense of less profitable services to patients with more serious/severe illness [Pfister, 1995].

In Canada, similar trends are likely to occur [CMQ, 1997; CST, 1992]. In the early 1990s there were 600 Canadian medical equipment manufacturers and distributors, among which 90% were in the small/medium entreprises category. Approximately 450 of these companies are currently in the business of providing technology for ambulatory care, including home care. In 1992, a study of the Canadian medical equipment sector [CST, 1992] highlighted five trends to help explain such an increase in activity: 1) the ageing of the population; 2) the increased use of information technology in homes; 3) the prevalence of a knowledge-based economy; 4) a growing delegation of responsibility to patients and society; and 5) substitution of hospital-based care by home care. It was anticipated that the Canadian medical technology market would reach $6 billion in 2000. Analysts have also predicted that Canadian companies will invest in R&D activities in order to create equipment for non-hospital-based use [CMQ, 1997; CST, 1992].

In this context, manufacturers have been developing sophisticated devices, most of them requiring less space and less medical expertise to operate. The American National Association for Medical Equipment Services (NAMES), founded more than fifteen years ago, includes 1600 companies that provide and deliver home medical equipment [Zarbock, 1997]. Whereas pharmacies often provide basic equipment such as canes and walkers, home medical equipment (HME) companies provide oxygen, wheelchairs, and hospital beds. The range of equipment and supplies provided by HME companies has broadened over the years. Sleep apnea monitors, infusion pumps, nebulizers, and infant phototherapy products are becoming more commonly available. Furthermore, these companies have widened their scope of services to include: intake assessment; communication with referring doctors; determination of medical necessity; patient and home evaluation; communication with other agencies; medical documentation; delivery of supplies and equipment; patient and caregiver education and training; equipment maintenance, cleaning, tracking, and pick-up; and billing and collections [Hamill, 1997]. NAMES acts as a legislative/regulatory advocate before Congress, the Federal Drug Administration, and the Health Care Financing Administration (HCFA). To our knowledge, no organization equivalent to NAMES exists in Canada.

2.1.3 Policy-making environment

Larsen [1996], commenting on the diversity of home care programs implemented across the Canadian provinces/territories, identified nine overarching emerging policy trends that will have an impact on home care services at a broad level (Box 1). The importance of these observations has been reiterated in recent Canadian policy-oriented studies [Parent and Anderson, 2001; Hollander et al., 2000].

BOX 1

The impact of nine policy issues on home care

1. The **decentralization of government** results in a greater responsibility for local decision-makers who, first, need to be sufficiently informed and then, be able to deal with the related issues of self-regulation and autonomy of community-based care.
2. The emphasis on an **integrated continuum of care** pushes home care providers to work in collaboration with new partners (who are often more powerful) and requires the development of new coordination mechanisms.
3. Reduced federal transfers to the provinces/territories, important cutbacks at the provincial level, and other **cost containment** initiatives compromise the viability of the Canada Health Act in the area of home care. For instance, preventive services are threatened and resource reallocation does not necessarily follow shifting needs of communities.
4. The growing role the **private sector** plays in the delivery of home care, and which varies considerably from one province/territory to another, raises important policy questions.
5. There is also an increasing call for **quality of care and clinical outcomes** evaluation advocated by researchers, providers, and health care managers. What type of information is available to monitor organization and delivery of home care services? Are there home care standards that can be agreed on at the national level?
6. An international shift towards greater public awareness and **consumer empowerment** necessitates a meaningful involvement of consumers in the process of planning and delivery of services, and the development of public accountability mechanisms as well.
7. New creative **resource management strategies** should recognize that home care staff will have to work in teams involving both professionals and non-professionals, and should seek to identify the minimal level of skill required.
8. The **management of information and the use of new information technology** remain underdeveloped in home care services, although they represent important opportunities to change the overall role of home care workers.
9. Finally, an **aging population** has obvious implications for the type of care that will be required, on the one hand, and the social support and caregiver network that will be available on the other hand.

Indeed, home care services are facing both challenges and opportunities. Regionalization is promoting competition, a balanced mix of private and public providers is being sought in several provinces/territories, and the scope and extent of contracting-out services is rapidly changing. In such a context, building trust and mutual respect is critical, especially because the "private sector must recognize that publicly funded organizations must deal with the philosophy that public monies should not be used to help others generate profit" [Larsen, 1996, p. 52].

2.1.4 Social environment

Another reason for the growth of technology-enhanced home care is that patients, families, and the overall social environment are often seen as receptive to such changes, wishing to obtain the best of all worlds: "state-of-the-art medical technology deployed in the privacy of one's home by loving family and friends" [Arras and Dubler, 1995, p. xiv]. Nonetheless, one should be cautious when referring to such a 'social demand' for home care. Several observers have warned about the entrepreneurial aspect of the home care industry [Arras and Dubler, 1995; Pfister, 1995]. For example, among cancer patients with incurable disease and limited therapeutic options, many individuals are eager to gain access to new therapies even if their efficacy is unproven [Pfister, 1995]. Before clarifying what technology is currently available to patients and providing some examples of such interventions, the next section presents an overview of the regulation and funding of home care in Canada.

2.2 REGULATION OF HOME CARE: GENERAL DEFINITIONS

Home care is included in the Canada Health Act as an Extended Health Care Service, although home care services are not publicly insured in the same way as are hospital and physician services. Home care is not regulated by the five Canada Health Act principles (i.e., public administration, comprehensiveness, universality, portability, and accessibility). As a result, Canadians face varying eligibility criteria, cost (in terms of public expenditure and user fees), quality, and access to home care services across the country [MacAdam, 2000]. Six provinces have introduced legislation related to home care: British Columbia, Alberta, Saskatchewan, Ontario, New Brunswick, and Nova Scotia [Dumont-Lemasson et al., 1999]. Manitoba and Prince Edward Island have Orders in Council establishing their home care programs. Québec, Newfoundland, the Yukon and the Northwest Territories have guidelines governing the delivery of home care but do not have specific legislation. Five major trends within jurisdictions emerge from current initiatives undertaken by the Canadian provinces and territories: 1) significant resources are being invested for the establishment of health information networks; 2) standardized assessment instruments are being developed and/or reviewed; 3) accountability frameworks and mechanisms are being devised, including evaluation of outcomes and performance measures; 4) concerted efforts are being deployed to develop standards for workers' job descriptions and categories; and 5) there is pressure for the increased integration of services in almost all provinces/territories [Dumont-Lemasson et al., 1999, p. 31]. Several observers have suggested that the time is ripe to strengthen home care services by adopting a "Canadian approach" that would include a national policy and standards developed in partnership with the provinces/territories [MacAdam, 2000; Parent and Anderson, 2000; Thompson, 2000; see also Coyte, 2002]. The Romanow Commission recommended that the Canada Health Act be revised to include coverage for home care services in three priority areas: mental health, post-acute home care (including medication management and rehabilitation services), and palliative care services to support people in their last six months of life [Romanow, 2002, p. 172]. It was also suggested that the Home Care Transfer be used to free up a substantial amount of funds in current home care budgets. "Provinces and Territories should immediately be able to use those freed-up resources to expand services and address the pressing home care needs of people with chronic conditions and physical disabilities" [Romanow, 2002, p. 187].

2.3 FUNDING AND UTILIZATION OF HOME CARE IN CANADA

National funding and utilization data for the home care sector have not been collected on a routine basis. The Health Canada publication *National Health Expenditures in Canada* does not include a specific category for home care as it does for physicians or hospitals. Statistics Canada has only recently become involved in collecting data in the home care sector. According to the Canadian Institute for Health Information [CIHI, 2003b], "There is currently no source of high quality, comparable pan-Canadian information to support evidence-based decision-making at regional and provincial/ territorial levels." The same is true for the province of Québec: "*Aucun système d'information encore n'était en mesure de fournir l'ensemble des données nécessaires pour mesurer de façon exacte l'utilisation de ces services et les coûts qui en découlent*" [MSSS, 2001b, p. 69].

A fairly recent agreement between the Premiers and the federal government regarding accountability may help the Canadian Institute for Health Information (CIHI) to include home care data in its reporting systems [MacAdam, 2000]. In 2002, CIHI completed Phase I of a major project, which involved identifying information needs and indicators that could be compiled for home care using existing data. As of October 2003, the most recent update from CIHI issued in March 2003 [CIHI, 2003b] confirms that the results from the national pilot test (Phase II: "testing the feasibility of collecting standardized data elements") conducted in six health regions (Newfoundland, Manitoba, Saskatchewan, Alberta, British Columbia, and the Yukon) were not yet available. It is anticipated that by the end of 2004 "consensus will be reached on the indicators and reporting data set, providing a foundation for comparable reporting of home care information in Canada."

Several important reports that examine home care programs across Canada have nonetheless been published [Hollander, 2002; Hollander and Chappell, 2002; Arundel and Gouberman, 2001; Parent and Anderson, 2001; Hollander et al., 2000; Anderson and Parent, 1999; Dumont-Lemasson et al., 1999; CHCA, 1998]. Together, these reports and special issues in Canadian journals [Laberge et al., 2000; Thompson, 2000] provide the most comprehensive overview of home care in Canada and a thorough analysis of the current issues in the delivery of these programs. During this period, the paucity of data on home care prompted Health Canada, in collaboration with the Canadian Home Care Association (CHCA) and Statistics Canada, to bring together the available data on provincial and territorial home care in a report [Dumont-Lemasson et al., 1999]. This Health Canada report updated and expanded on the CHCA publication using a variety of sources of data (including Statistics Canada and Health Canada), and involved provincial and territorial representatives in the clarification and review of its content. Despite the problems inherent in aggregating data from various home care programs across Canada, these reports provide detailed information about the programs in each province and a comparative analysis of organization,
legislation, programs and services, and recent initiatives.

Home care programs exist in all provinces and territories in Canada. The definition of care, funding, standards, terminology, and data collected are unique to each program, given provincial responsibility for health care and in the absence of a national home care policy or program [MacAdam, 2000]. Most provinces/territories have delegated responsibility for funding allocation and service delivery to regional or local health authorities. In most cases, the provincial/ territorial departments define the overall policy guidelines and standards (i.e. service delivery, reporting requirements, outcomes monitoring) [Dumont-Lemasson et al., 1999, p. 13]. The trend in recent years has been towards the allocation of funds according to a population needs based model.

As stated above, Health Canada reports that total public funding for home care has increased over recent years, from $1.028 billion in 1990-91 to $2.096 billion in 1997-98. This represents an annual average rate of increase of almost 11% [Dumont-Lemasson et al., 1999]. However, information about the funding levels for the different home care programs in Canada varies in completeness from one source to another. Provincial and territorial sources generally exclude First Nations and other federal investments. The proportion of total health expenditure—including national funding sources for First Nations, veterans, provincial, and municipal home care services—allocated to home care in 1997-98 varied from less than 2% to 6% amongst provinces/territories. These figures include assessment, case management, nursing, personal care services, physiotherapy, occupational therapy, homemaker services, and meal programs. They exclude home support services that are not related to health problems, and do not include the costs of drugs, medical equipment, and supplies. Manitoba, Ontario, New Brunswick, and Newfoundland invested more than 5% of their provincial budget in home care programs; Saskatchewan and British Columbia between 3% and 4%; Alberta, Québec, Prince Edward Island, and the Northwest Territories between 2% and 3%; and the Yukon less than 2% [Dumont-Lemasson et al., 1999, p. 25]. Table 1 summarizes the findings on funding and current issues for home care programs across Canada.

TABLE 1

Funding and issues in home care across Canada

	PUBLIC EXPENDITURE* (99/00; THOUSANDS)	PUBLIC EXPENDITURE* (99/00; $ PER CAPITA)	ISSUES†
Yukon (YT)	$2,767	$90	Growing needs in home care; Pilot-testing of integrated case management system and information system; Methods of providing intravenous care in rural areas; Lack of formal evaluation of program outcomes; Lack of an adequate database.
Northwest Territories (NWT)	$3,500	$84	Cross-cultural awareness; changing the concept of home care; Small isolated communities; hiring qualified staff and staff training and retention; Hospital-to-home care protocols; increasing number of mental health clients; need for day services; New funding arrangements for medical and non-medical supplies; Increased needs in terms of family support; Education of the public about guardianship.
British-Columbia (BC)	$349,000	$87	Relationships and communication in the context of regionalization; Requirement for accountability and reporting tools; Balance between provincial and regional levels; Appropriate use of services as community services increase.
Alberta (AB)	$199,000	$67	Consistency between the 17 RHAs' Home Care Programs (standards, equal access, and portability); Shift to the least skilled provider raising issues of shared competency and transfer of function; Volumes of clients; Safety in the workplace as more clients are served at night and on weekends; Regional variations in user fees; New, inexperienced home care staff.
Saskatchewan (SK)	$75,544	$74	Outcome standards, support to family caregivers; Inter-sectorial collaboration (education); Recruiting part-time staff in rural areas.
Manitoba (MB)	$147,232	$129	Appropriate information systems and staffing mix; Seven-day-a-week care coordinated by a five-day-a-week organization; Changing client demands and profiles; Training and recruitment of care service workers; Casual work force; delegation of function from nursing to non-professional staff; Role and expectations of family caregivers.

Funding and issues in home care across Canada (cont'd)

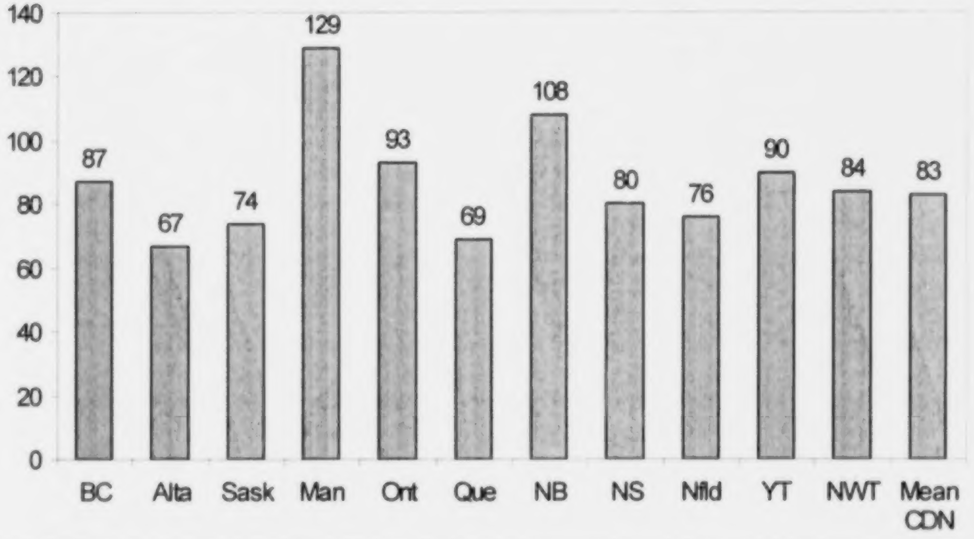
	PUBLIC EXPENDITURE* (99-00; THOUSANDS)	PUBLIC EXPENDITURE* (99-00; $ PER CAPITA)	ISSUES†
Ontario (ON)	$1,064,812	$93	Need to examine the impact of the reduction of acute care beds on home care; Shift of jobs from hospital facilities to the community; Need for an information system that will reduce the time spent on routine tasks; Development of a new information system, based on SACPAT.
Québec (QC)	$508,703	$69	Interface with hospitals (communication mechanisms, access to specialized personnel and equipment, integration of the work force coming from hospital, protocols, and agreements); Integrated continuum of services for long-term clients (private sector, social economy, merger of CLSCs with other CLSCs or CHSLD); Public coverage (access criteria, CLSC vs. hospital rules); Indicators for measuring access, effectiveness, appropriateness, and outcomes of services.
New Brunswick (NB)	$81,192	$108	Implementation of the EMP after structural change; Development of processes to ensure transition of EMP to the management of the eight RHCs; Policy and procedure development; Development of new decision-making processes for equitable allocation; Determination of information needed to ensure efficiency, cost-effectiveness, and consistency of services; Gathering of relevant data that will contribute to evidence-based decision-making at all levels; Raising public awareness of home care.
Nova Scotia (NS)	$75,075	$80	Role of care coordinators; Development of a single point of entry; Technological and communication infrastructure; Hiring and retention of staff.
Prince Edward Island (PEI)	NA	NA	Integrated information system; Hospital to home care protocol; Coverage for supplies and medication; Prevention and management of depression and dementia; Lack of trained staff; Identification of caregiver burden and prevention of burnout.
Newfoundland (NF)	$41,000	$76	Development of a comprehensive information system; Programming of services outside the hospital or physician's office; The need to address the psychosocial as well as the physical dimensions of client care; Development of research on better planning models of community needs assessment and resource allocation; Co-ordination of government programs.

*Source: MSSS, 2001a. Data were collected from provincial representatives. Data about Saskatchewan are for FY 1998-1999.
†Source: CHCA, 1998.

According to data provided by the MSSS *Direction de la planification stratégique*, Manitoba had the highest per capita spending ($129) in 1999-2000 while Alberta spent the least ($67) (see Figure 1). More recent data indicates that the mean per capita public home care expenditures level in 2000-01 is $87.51, with Québec ($69) remaining under this mean [Coyte, 2002].

FIGURE 1

Per capita expenditures for home care ($CDN, 1999-2000)



Source: MSSS, 2001a. Data were collected from provincial representatives. Data about Saskatchewan are for FY 1998-1999. Data about PEI were not available.

According to Coyte [2002], the rate of growth of *public* home care expenditures in Canada has been declining (from 17.2% in FY80-FY90 to 8.9% in FY95-FY00) while the rate of growth of *private* expenditures has increased (from 9.4% in FY80-90 to 15.6% in FY95-00). This author argues that $1.5 billion should be invested at the national level to ensure that all Canadians have access to a similar level of public home care funding. Following this scenario, the Province of Québec should increase by 159.3% its current level of public expenditures ($382.5 million) to $609.2 million.

In summary, the available information from federal and provincial/territorial sources show important variations across provinces/territories in the level of per capita public expenditure for home care.

2.4 SIMILARITIES AND DIFFERENCES ACROSS CANADA

The state of home care in Canada has been clarified in recent publications reviewed in this report [CARP, 2001; Thompson, 2000; Dumont-Lemasson et al., 1999; CHCA, 1998], and the policy climate is ripe for debate with respect to the best way forward. Most provincial/territorial programs are still in a period of growth and development, adapting to overarching changes in local, provincial, and national health systems. According to the most salient **similarities** amongst provinces/territories include: 1) the responsibility for home care falls under the department/ministries of health; 2) a common base of services (including nursing, personal care, and homemaking services) is available in all provinces/territories; 3) a diverse clientele is served (with respect to age, health status, and medical and social needs); 4) a set of similar basic requirements for eligibility is applied (e.g. provincial/territorial health insurance, residence, unmet needs, client consent, and home safety); 5) measures to coordinate and integrate services (e.g. single point of access, comprehensive needs assessment, case management) are in place; 6) the case management function is carried out by public employees; 7) there is movement towards standardization with respect to, for instance, assessment tools and information systems; 8) nursing services are provided without charge to the clients (although limitations in terms of client eligibility, and duration and intensity of services may apply), and most provinces require patient co-payments and/or some form of income assessment; 9) there has been investment in the home care sector despite fiscal constraints; 10) responsibility for home care has been regionalized in most areas, giving more flexibility (in terms of funding responsibilities and priority-setting) to regional or local authorities; 11) the training of unregulated workers, division of tasks between unregulated and regulated workers, as well as staff recruitment, are key issues in most areas; and 12) increased activity, developmental initiatives, and research are noticeable in most provinces/territories.

The main **differences** across provinces/territories are: 1) the regulatory status of home care programs is limited, uneven, and varies greatly across jurisdictions (e.g. professional home care and homemaker services often fall under two different regulatory arrangements); 2) policies and procedures for charges to clients for home support services vary (for instance, priority is given in Québec to low-income clients without formal income testing); 3) the range of professional services available varies and is generally narrower in rural and isolated areas (speech therapy, dietetics and social work are less available than other services); 4) the models of service delivery reflect a diverse mix of public and private sector workers (e.g. in Ontario, there is an open competitive model where either for-profit and not-for profit agencies can compete); 5) although levels of funding have been increasing in most jurisdictions, the range of per capita funding varies substantially; and 6) there are variations in policy in certain areas regarding, for instance, equity, access, service standards, obligation for family members to provide care, and client obligation to pay for publicly-funded services.

Given the limited amount of regulation applicable to home care, and in the absence of a national policy or program, Canadians face varying eligibility, cost, quality, and access issues concerning home care services across the country [MacAdam, 2000]. Each province/territory has made specific arrangements for the funding and delivery of home care, while regional authorities have played an increasingly important role in the organization of services. Except perhaps through the Boards of Community Care Access Centres (CCACs) in Ontario, consumer involvement appears limited and inconsistent across provinces/territories and regions. Mechanisms to increase consumer input could be developed at different levels, to include involvement in priority-setting, and the organization and evaluation of home care services. Finally, even though several provincial/territorial programs have stressed that high-tech home care is an issue in their jurisdiction, no formal national policy to ensure safe, cost-effective, and patient-centered use of technology has been developed.

2.5 TECHNOLOGY IN HOME CARE: SOME EXAMPLES

According to Kaye and Davitt [1995a], the most frequently provided technology-enhanced home care services are **infusion therapies**, including artificial nutrition and hydration, antibiotic therapy, pain management, and chemotherapy. For all infusion therapies, the venous access device chosen raises different sets of safety issues (see Box 2 for details). The implications for home care service agencies are the need for 24-hour coverage for all patients, ensuring appropriate levels of nursing skills among staff, and establishing collaborative links with physicians.

BOX 2

Infusion therapies: venous access and catheters

- **The peripherally inserted central catheter (PICC)** is used frequently for short-term venous access. The PICC is associated with reduced risk of infection and air embolism and can be used for antibiotics, chemotherapy, palliative care, parenteral nutrition, blood sampling, and drugs. However, the PICC is not suited for high-fluid volume infusions, rapid bolus injection, or hemodialysis.
- The **tunneled catheter** (Hickman/Broviac and Groshong), which is implanted surgically under anesthesia, is better suited for long-term access for patients requiring repeated, intensive supportive therapy, infusion of vesicant chemotherapy, or long-term nutritional support.
- The totally implanted venous access ports (or **Implanted Vascular Access Devices: IVADs**) are comprised of two parts: the catheter that is inserted into a large vein, and the port that is implanted under the skin. IVADs, because of the closed system they create, eliminate the need for daily site care, and allow the patient to retain a closer-to-normal lifestyle.

One of the most common types of infusion therapy is **artificial nutrition and hydration**, or tube feeding. Two routes for delivering fluids to patients who are unable to swallow or absorb food are: 1) enteral nutrition, for providing nutrients directly into the stomach via a tube; and 2) parenteral nutrition, for providing nutrients through venous access. Enteral nutrition, as an invasive procedure, carries risks of infection, of mechanical failures, and of digestive or metabolic complications (vomiting, pulmonary aspiration, nutrient deficiencies), that can be reduced by proper monitoring of the patient, formula preparation, and nutrient administration. Because parenteral nutrition involves the use of a catheter through which nutrients are diffused at night with a programmable pump, patients must know how to connect the infusion to the catheter, redress the entry site, program the pump, disconnect and flush the catheter, and irrigate a blocked catheter (see chapter by Okun in Arras and Dubler [1995] for historical details about total parenteral nutrition [TPN] development, and Law and Lehoux [2001] for a detailed review of the literature). A multidisciplinary teamof professionals should be responsible for evaluating the patient before discharge, whereas a nutritional support specialist is required immediately after discharge. Patient (and/or caregiver) education is essential as well, given the res-ponsibilities for self-care listed above. Patients need a solid understanding of antiseptic/sterile procedures to prevent infection, of potential complications, and of appropriate responses in an emergency.

Home therapy services for **cancer** are also increasing in number and variety. Solid tumors at four primary sites (lung, colon/rectum, breast, and prostate) account for over 50 percent of the incidence and mortality of cancer. Available systemic therapies for these diseases are typically palliative, not curative. As noted by Pfister [1995, p. 65], "while patients with certain advanced and/or metastatic tumors (e.g. adult and childhood leukemia, lymphoma, childhood sarcoma, testicular cancer) are now routinely cured with the addition of available systemic therapies, these diseases unfortunately represent less than 10 percent of cancer diagnosed in the United States each year." Therapeutic modalities for cancer can be associated with substantial side effects. The initial management of these toxicities begins in the hospital and many patients can have their treatment completed at home. Self-administration is a challenge with a severely debilitated patient, where the dependence on a caregiver is greater, and the potential for treatment toxicity increases [Pfister, 1995, p. 75].

Patient-controlled analgesia (PCA) is a new but widely accepted approach to pain management in acute care hospitals, most specifically for postoperative pain [Pousada, 1995]. PCA permits patients to deliver analgesia on the basis of their own perception of need. Due to physicians' assumptions about the capacity of elderly patients and their families to manipulate complex devices, a relatively slower growth in the use of PCA among elderly patients has been observed. However, the use of PCA is not limited to the use of mechanical systems, as analgesics may be administered sublingually, via inhalation, rectally, subcutaneously, or orally.

The **Automatic Implantable Cardioverter Defibrillator** (AICD), developed in the early 1980s in the USA, is an example of specialized equipment which use could be increasingly monitored by home care service providers. This treatment is considered high-tech because of its complexity, novelty, and the nursing and medical knowledge required to adequately monitor patients. The AICD, approved by the FDA in 1985, is used with patients who have ventricular arrhythmias (tachyarrhythmias) that are not treatable through conventional drug therapy. Recent advances have produced a device that can pace the patient out of tachycardia (antitachycardia pacing or ATP), provide cardiovascular defibrillation, and bradycardia pacing. AICD patients—many of whom are over 60 years old—often experience serious psychological distress after implantation, such as fear of 'overshocking', fear of sudden death, and loss of independence [Kaye and Davitt, 1995, p. 84]. It is recommended that an emergency response system be put in place before patients return home, and family members are encouraged to obtain CPR instruction. Education for both the patient and caregiver is crucial in that it should help reduce anxiety and promote appropriate emergency actions.

Kaye and Davitt [1995b] expect that several technological developments in the field of **information technology** will transform home care services in the near future. These advances relate to robotics, sensory stimulation devices, adaptive computer hardware, voice-activated systems, interactive telecommunications systems, and computer-assisted self-care/self-help instructions. These technologies thus refer to the second category of high-tech home care identified earlier, home adaptations and environmental designs. Home telecare is a growing application of telemedicine. Chronic patients with life-long diseases (e.g. cystic fibrosis, diabetes, pulmonary obstructive disease) can represent target groups for educational, preventive, and follow-up purposes. Hospitalizations due to infections or treatment imbalance can be prevented in a timely fashion through the remote supervision of clinical information transmitted electronically. Other conditions (e.g. high risk pregnancy, sleep apnea) can also be monitored for shorter periods of time. Information technology will also exert indirect impact on health care services. For instance, Pfister [1995] anticipates that the next generation of programmable infusion pumps will build on advances in communications technology. The new pumps will support a more sophisticated monitoring of services and may decrease the need for home visits: physicians will be able to modify drug flows from a distance. More broadly, the implementation of information systems in community health centres may lead to a better understanding of the costs and effectiveness of home care interventions.

Personal Emergency Response Systems (PERS) have been available for about 10 to 15 years and come in different electronic forms, the most common being a small transmitter a patient wears around his/her neck or wrist. Such a transmitter can signal to a central response station when a person has been inactive at home for a certain period of time, or when a person needs help. The station can then call him/her, contact neighbours or family, and/or alert local ambulance/fire services. There is a wide diversity of systems on the market (e.g. voice activation, inclusion of smoke detection, monitoring of medical equipment, etc.). The alarm systems most widely used in the USA require a $75 installation fee and a $35 monthly connection charge [Pousada, 1995]. These are not covered by Medicare or third-party insurers. As recently described by Bastian [1998], home care services represent an area where consumers are likely to play an active role. For instance, the American Association of Retired Persons [1992, cited in Kaye and Davitt, 1995b] has published a report in which 20 different PERS are reviewed and their performance discussed.

Pressure sores (decubitus ulcers) are a recurrent problem for geriatric patients with chronic diseases. A six-fold increase in mortality is associated with the development of a pressure sore, although it is not clear whether this is due to the presence of multi-systemic disease [Allman et al., 1986, cited in Pousada, 1995]. **High-tech**

beds are of two sorts: alternating-pressure air mattresses—which consist of a series of compartments filled with air, connected to pumps inflating and deflating the compartments cyclically—and air-fluidized beds, which contain bead-like ceramic spherules through which filtered air is circulated, thereby simulating fluid movement. These beds reduce capillary filling pressure, eliminate shear and friction, reduce bacterial growth, and decrease pain. The disadvantages of these beds are the risk of mechanical malfunction, the need for frequent servicing, the bulk and weight of the beds, and the risk that the patient may develop dehydration and confusion related to sensory deprivation [Pousada, 1995]. Their cost varies from $20,000 to $35,000, and rental runs between $50 and $200 per day.

As a final example, an inexpensive technology used with elderly patients is **urinary tract catheterization**. Urethral catheters can be put in place by patients, family members or medical personnel and can be either indwelling or intermittent. Subrapubic catheters are placed surgically and are indwelling; these require regular monitoring by a urologist. The tubing is attached to a urine-collection bag that can be strapped to the leg. This technology is relatively noninvasive and requires little monitoring in the home setting.

2.6 TECHNOLOGY AND FUNCTIONS OF HOME CARE

The technologies discussed above are not influencing the provision of home care in a consistent fashion. It is possible to define their role in greater detail by highlighting their compatibility with the diverse functions of home care programs. Home care programs with a mix of three functions can be found in each province and territory today [Larsen, 1996]. First, the **maintenance/preventive function** aims to provide services to persons whose social or functional status would deteriorate otherwise and would lead to admission to a long-term care facility. Personal assistance, meals-on-wheels, and counseling are services typically delivered according to this function. Second, the **long-term care substitution function** renders services to persons who need the type of care that long-term care facilities provide. Clients are referred either by hospital or community services. Finally, the **acute care substitution function** aims to provide these services to patients who would remain in acute care facilities in the absence of home care. Access to services is more restrictive, is based on a limited number of days of services, and requires physician referral.

These three categories were applied in a literature review on economic evaluations of the cost-effectiveness of home care [HSURC 1996a], and can also be helpful in classifying the potential effects of diverse technologies used in home care. For instance, IV therapy clearly belongs to the acute care substitution category (e.g. services previously hospital-based are transferred to CLSC home care programs). Home dialysis and parenteral nutrition could also reduce the need for acute care by preventing repetitive readmissions of chronically ill patients. Finally, home adaptations and environmental designs support a preventive function by assisting elderly persons to remain independent longer in their own homes. A more critical examination does, however, indicate that beyond analyzing the potential effects of each technology separately, it may be more instructive to reflect on the cumulative and systemic effects produced by the introduction of the full set of these technologies. In other words, one should recognize the broader global change triggered by technology in general. It seems reasonable to expect that, as a whole, technology-enhanced home care will influence all of these overlapping home care delivery functions in a sufficiently profound manner that it can be considered a new model of home care delivery in itself.

2.7 DEFINITION OF THE PROBLEM ADDRESSED IN THIS REPORT

Technology-enhanced home care can indeed be seen as the hybrid result of several threads of change, contributing to a new model of home care delivery. Its rapid growth is fed by political, technological, clinical, social, and commercial factors. This new model may act synergistically with existing community-based home care models or it may clash with them. This model clearly implies new collaborations (i.e. providers and managers from both hospitals and community care centres must coordinate their actions), new categories of users (i.e. patients and caregivers who are not passive recipients of care but must be active participants), and new settings (e.g. urban apartment buildings, flats, rural houses, etc.). Consequently, four problems implicit in a shift to technology-enhanced home care require immediate attention.

2.7.1 Problem 1: The weak interface between community-based and specialized hospital-based home care

In Québec, the local community health centres (CLSCs) have historically focused on illness prevention and health maintenance objectives for elderly clients within their territory, aiming to preserve their autonomy as long as possible and delay their admission to a nursing home. The localized and personalized focus in home care programs is increasingly redefined as new home care interventions are being developed, often relying on the use of specialized equipment with patients from diverse age groups (e.g. children, pregnant women, young adults). Hospital-initiated changes, backed by the "*virage ambulatoire*", are forcing CLSCs to reconsider the content and priorities of their programs. For instance, agreements for IV therapy have been signed between hospitals and CLSCs which specify explicitly the post-acute services that CLSC nurses will provide to patients discharged by the hospital [Lehoux et al., 2001b]. These services are acute, delivered for a very short period (compared to preventive home care for the elderly), and generally concern adults. CLSC staff are thus facing a different clientele, with different needs, while operating in conditions where the relationship with the patient (teaching the patient to become autonomous) takes place during a short period of contact.

There is another side to this coin: hospitals are actively developing ambulatory and home care services for patients with both acute and chronic diseases, where patient education and health promotion are of prime interest. Such hospital-based home care programs (e.g., parenteral nutrition) require easy access to medical expertise, well-trained nursing staff, multidisciplinary teams, and specialized equipment. In other words, both CLSCs and hospitals are extending their traditional frontiers in terms of home care delivery. It is uncertain, in this shifting context, whether—and how—health care managers and care providers from both hospitals and community health centres are adapting to their new roles, and to what extent they can adequately coordinate their interventions. One should keep in mind that the discharge of a patient from the hospital is an important event in the episode of care which, in itself, usually generates anxiety for both the patient and his/her caregiver(s).

2.7.2 Problem 2: Increased responsibility delegated to patients and caregivers

According to the Romanow Commission [2002, p. 181], "discharging people early from hospital without adequate resources simply shifts the burden for care from hospitals to patients and their families." Furthermore, despite the fact that home-based patients and their caregivers must learn and master more technical knowledge and skills in comparison to hospitalized patients, very few studies have investigated the knowledge and skills required to manipulate home care technologies appropriately and independently. The use of technology at home often relies on the delegation of important clinical/technical tasks and responsibilities to the patient and caregiver. Some technologies impose considerable burden on patients and their families. Relationships between formal care providers and patients (and informal caregivers) are being redefined. If one presumes that nurses and home care team members are doing their best to teach and supervise patients according to their individual learning ability, significant variations among patient groups (defined by age, fine psychomotor skills, linguistic skills, attitudes towards health care, etc.) still remain, in terms of ability and willingness to learn and routinely apply clinical skills. A transfer of responsibility to patients and caregivers assumes that clinicians have been successful in communicating risks and clarifying emergency procedures. Social inequalities (in terms of income, education, or ethnicity, for example) may affect the ability of patients to benefit from home care. Some may be excluded on the basis of poor understanding of technical aspects (due to language or cognitive ability barriers) or inappropriate home environments and community support. These variations should be taken into account when assessing technology-enhanced home care programs as their overall cost-effectiveness will be affected by such differential access. In fact, the increased use of home care is part of the "quicker, sicker phenomenon", whereby patients are being discharged earlier and home care clients are often sicker when sent home [Zarbock, 1997]. Questions about access, equity, quality of care, and the consequences of such care for patients and their families remain insufficiently addressed. There are important ethical, social, and legal aspects linked to the delegation of clinical tasks and responsibilities.

2.7.3 Problem 3: Medicalization of the home

The "*virage ambulatoire*" implies that the utilization and sophistication of health care technologies will increase in patients' homes—a setting that differs from the hospital in terms of infrastructure, quality control, and safety measures. The emotional meaning attached to 'home' tends to 'romanticize' the home as a care delivery setting [Arras and Dubler, 1995]. It is therefore often taken for granted that most "typical houses" would be suitable for the delivery of home care. Nonetheless, the homes of chronic care patients can become "small hospitals", due to the use of specialized equipment and drugs, and the need for a sterile environment and storage room. The full implications of adapting the home environment for the delivery of specialized care has not been extensively investigated in the scientific literature. Providing care in the patient's home can modify—sometimes radically—the way patients and caregivers will perceive and react to a medical condition. This raises several questions: Are all home environments alike? What differences are important in terms of outcomes? Are homes safe places to deliver care? What happens when patients do not have access to safe and appropriate home environments? There are also questions about who is ultimately accountable for quality of care and outcomes, when patients and caregivers are mainly responsible for using the medical devices properly.

This change in the context of the use of technologies may not be simply a matter of hygiene or supervision. It may involve more complex dynamics, such as risk taking, and impact on psychological well-being, family relationships, or social networks. Practical aspects may play a role in unpredictable ways: Can emergency situations be dealt with in a standardized manner across a province? Should disposable products and biological waste be put in the domestic trash? Is it possible to minimize the risks associated with the behavior of children or pets? What are the limitations that a technology may impose on a patient's mobility and freedom of movement? We believe that such a seemingly trivial and marginal combination of human and technical factors defining the level of 'user-friendliness' of a given technology may reduce its effectiveness [Lehoux et al., 2001b]. User-friendliness is comprised of several aspects, such as manipulation burden, simplicity of use, behavioral constraints, the level of anxiety triggered, appearance, etc. For example, oxygen therapy was perceived as being very simple to manipulate, although it imposed more stringent constraints on behavior ("being tied to the machine for 18 hours daily"), and its use carries risks of fire [Lehoux et al., 2001b]. While occupational therapists have a key role to play in ensuring that appropriate home adaptations will be implemented and that assistive devices will be used whenever necessary, it is nonetheless important to understand the barriers and risks to health that inappropriate home environments may represent. Finally, according to Arras and Dubler [1995], instead of "blindly" promoting high-tech home environments, one could examine the alternative of creating a variety of institutions that could better respond to certain patients' needs. As much as home is seen as a better place compared to the existing nursing homes or long-term care facilities, would it be possible to imagine a new type of institution that would be user-friendly?

2.7.4 Problem 4: Implementation of programs despite the lack of evidence about their cost-effectiveness

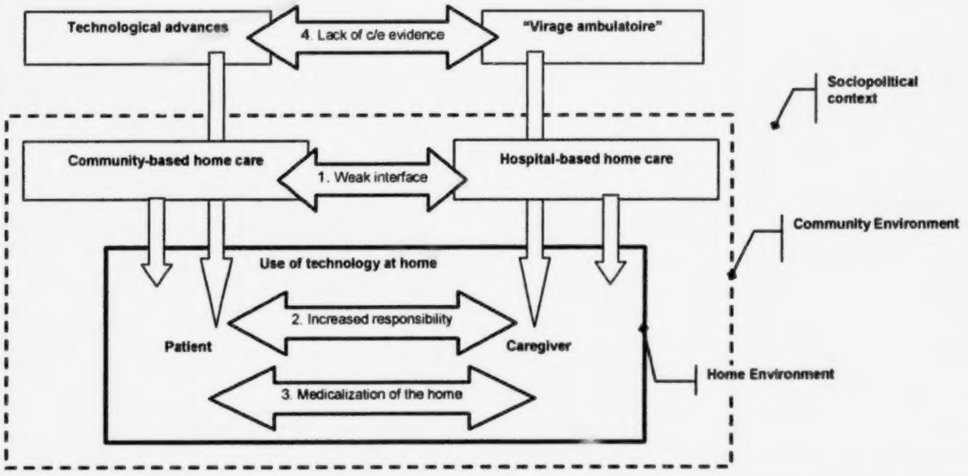
According to the synthesis report of the National Evaluation of the Cost-Effectiveness of Home Care program, which integrated 15 studies conducted across Canada, "at present time there are relatively very few areas noted in the literature where home care has been shown to be a cost-effective alternative to hospital care" [Hollander and Chappell, 2002, preface]. In Québec, the *"virage ambulatoire"* includes all kinds of home care initiatives, some of which may be sound and cost-effective and others that may be not. Hospital care services are generally very costly. It is therefore often assumed intuitively that home care services are less expensive. However, private and public costs—as well as indirect costs—have often not been assessed consistently. It is not surprising that the literature shows conflicting results as some home care interventions are shown to be more cost-effective than hospital care, and vice-versa. Overall, there is a lack of convincing evidence and clinicians as well as policy-makers should carefully consider the provision of home care services involving particular technologies as an alternative to hospital care.

2.8 CONCEPTUAL FRAMEWORK

In order to structure our examination of the issues in organization and delivery of technology-enhanced home care, we propose a conceptual framework. Its main function is to organize the relationships that are explored in greater depth in chapters 3, 4, and 5 of this report, while focusing on the four problems described above.

FIGURE 2

Problematic issues in technology-enhanced home care


Technological advances
4. Lack of c/e evidence
"Virage ambulatoire"
Sociopolitical context
Community-based home care
1. Weak interface
Hospital-based home care
Community Environment
Use of technology at home
2. Increased responsibility
Patient
Caregiver
Home Environment
3. Medicalization of the home

The framework highlights three types of context or environment: 1) the broader **sociopolitical context** in which both health system reforms and technological advances foster the development of technology-enhanced home care, despite the lack of evidence about its cost-effectiveness (C/E); 2) the **community environment** wherein social support and local organizations (meals-on-wheels, transportation, volunteering, etc.) may supplement the home care services received by the patient and wherein continuity of care is of prime importance; and 3) the **immediate environment** of the patient, which includes the physical and familial settings where he/she receives care and the resources (e.g. physical, cognitive, financial) he/she can mobilize. It is within this last environment that social inequalities may be highlighted by the use of complex technology in home care, as increased responsibility for patients and caregivers may be more easily transferred to patients who are better-educated and in a higher socio-economic group.

3 TECHNOLOGY USED AT HOME IN QUÉBEC CLSCs

3.1 HOME CARE IN QUÉBEC

Home care services in Québec are part of the primary care mandate of the CLSCs (created in 1972) [CHCA–Québec, 1998]. CLSCs provide 40% of all home care services (currently 50% of their budget) delivered in the province. Three stages of development are apparent in the type of home services CLSCs have been delivering: 1) the establishment of local services with a preventive emphasis from 1975 to 1985; 2) the social integration of disabled and mentally frail persons through a wider scope of community services from 1985 to 1995; and 3) an increase in curative services provided as a substitute for, or in continuity with, hospital acute care services after 1995. The regionalization process, initiated in Québec in 1991, broadened the scope of CLSC responsibilities. However, the funding allocated to CLSCs for home care varies from one region to another, raising issues of access and equity. At the beginning of 2004, there were 147 CLSCs and multifunction health centres in Québec, each covering a population varying in size from 9,000 to 125,000. The recent creation of the now *réseaux locaux de services* by the merging of CLSCs between them or with hospitals will significantly modify this statistical picture.

The CLSC home care program is available to all individuals (children and adults) with temporary or permanent physical, mental, or social impairment who require services at home. The objectives of the program are to: prevent loss of autonomy; compensate for a person's impairments with family and/or community resources; provide respite and support to caregivers; prevent or delay institutionalization and unnecessary hospitalization; support community-based initiatives that promote social integration and local consultation; and coordinate access to public housing and day centres. CLSCs are accountable to the Regional Health Authorities (18 regions were established in Québec in the early 1990s). CLSCs may voluntarily seek accreditation from a provincial body of accreditation of health organizations. The *Ministère de la Santé et des Services sociaux* (MSSS) has defined several indicators to monitor and assess the performance and quality of home care services, such as the level of substitution for acute services, community access to services, and rates of institutionalization. CLSCs may use an information system (*système information-clientèle*: SIC) to track their program performance (e.g. evolution of caseload, types and volume of services, etc.). In addition, each new patient enrolled in the home care program has a personal file available for the nursing staff at *Info-Santé CLSC*, a 24-hour phone consultation service. Although the use of information systems remains uneven across the province, a common framework (*cadre normatif*) for gathering and reporting information is to be adopted in the very near future [MSSS, 1999].

Current home care services include: pre-assessment; assessment of health and social needs; service coordination; medical and nursing care; rehabilitation therapy and physiotherapy; family counseling, social work, and crisis support; support services (daily activities, personal care, meals, homemaking, and civil support); respite care and support group activities for caregivers; equipment rental (e.g. technical aids, oxygen concentrators, etc.) and dressings; access to public housing and day centres; and coordination of other community services/resources. Each CLSC manages its home care program with a certain level of autonomy. The maximum amount of services a client can receive varies from 35 to 44 hours per week (excluding professional services). Professional services are delivered by CLSC staff, while support and respite services can be provided by: 1) CLSC staff; 2) the client's family members themselves with the help of a financial allocation; or 3) a private agency (for profit or not-for-profit) or other community organizations (public, not-for-profit) contracted by the CLSC. Eligibility criteria include: residency in Québec, within the CLSC territory where the application is being made; needs assessment by a professional; agreement to participate; inability to receive services elsewhere than at home; and an appropriate home environment. Priority is given to those who have greater needs, whose situation is urgent or critical, whose family members are unable or unavailable, and who are socio-economically frail. Services are available 7 days a week, from 7:00 AM to 11:00 PM (some CLSCs are able to provide 24-hour care). There are no user fees, although clients are selectively enrolled in the long-term care program (elderly persons), taking budget constraints into account.

3.2 A SURVEY ON TECHNOLOGY USE BY QUÉBEC CLSCs

A study funded by the Canadian Institutes of Health Research [Lehoux et al., 1998] was conducted in 1999-2001 by the first author of this report (PL) with a research team based at *Université de Montréal*. The aim of the research was to identify the organizational, technical, and human factors influencing the use of technology in home care by CLSCs in Québec. Managers, professionals, patients, and caregivers were interviewed to gain insight into the barriers and opportunities associated with the use of IV therapy, oxygen therapy, dialysis, and parenteral nutrition [Lehoux et al., 2003; 2002; 2001b]. A mail-back survey was sent to 140 CLSCs. Four health centres from three regions (Nunavik, the Cree Territories and the North of Québec) were excluded; the contexts in which these organizations operate are different enough to justify the development of a separate study. A response rate close to 70% was obtained for the survey questionnaire (97/140=69.3%), which was considered satisfactory given the length of the survey (more than 30 close-ended questions), as well as the pressure under which CLSCs were operating—to reorganize and deliver home care services—at the time of the study. This section summarizes descriptive results from the survey; further analyses and results from the interviews are available in Lehoux and al. [2001a; 2001b].

3.3 TO WHAT EXTENT ARE TECHNOLOGIES USED BY CLSCs?

There were important variations in the use of the four selected interventions by CLSCs (see Table 2). The first question of the survey sought to measure the level of involvement in technology-enhanced home care by the CLSC: "Has your CLSC ever delivered care (on site or at the patient's home) involving the following technologies?" ("*Votre CLSC a-t-il déjà dispensé des soins [sur place ou au domicile du client] impliquant les technologies suivantes?*"). Respondents had to specify whether it was care "directly related" to the technology (i.e. flushing catheters, changing tubes) or "indirectly related" (i.e. changing dressings, monitoring of vital signs). A single answer was possible. This question thus yields information about the level of involvement in the delivery of technology-enhanced care by the CLSC.

Almost all CLSCs had been involved in IV therapy. The two most common modes of delivery were gravity (81.3% of CLSCs) and programmable pumps (97.9%) whereas the "nursing bottle" (e.g. a single-dose, entirely mechanical delivery system) was used less frequently (58.9%). There were important regional variations, some CLSCs using gravity for a vast majority of patients (78%) and others using the mechanical delivery system for only a small portion of patients (20%) (data not shown). Although the choice of the delivery system has a direct impact on CLSC human resources workload (i.e. gravity requires 2 to 3 one-hour visits per day), it is prescribed by the referring physician (usually hospital-based). IV therapy services were considered directly related in most cases. Oxygen therapy was the second most frequent home care service provided by CLSCs (with fixed concentrators: 83.5% of CLSCs), with services considered directly related in the majority of cases (about 60%). The provision of services related to parenteral nutrition was limited but still significant

(26.6% of CLSCs); services were reported as directly related in a majority of cases (54.2%). A significant proportion of CLSCs (78.1%) indicated having delivered peritoneal dialysis care. However, these services were considered directly related by less than one-third of CLSCs (31.9%). Table 2 also indicates that a large proportion of CLSCs had been involved in the provision of anticoagulant therapy services (87.9%), while a third (35.6%) had been involved in the delivery of IV chemotherapy. Despite the extensive literature highlighting the rapid growth of telehome care, the use of various information technology-based home monitoring services was limited.

TABLE 2

Utilization of selected technologies by CLSCs

TECHNOLOGY		EVER DELIVERED		DIRECT CARE		INDIRECT CARE	
	R	%*	N	%†	N	%†	N
IV therapy							
Gravity	96	81.3	78	97.1	68	2.9	2
Programmable pump	96	97.9	94	98.8	85	1.2	1
Mechanical system	95	58.9	56	96.2	51	3.8	2
Oxygen therapy							
Fixed concentrator	97	83.5	81	61.1	44	38.9	28
Portable cylinder	96	72.9	70	56.7	34	43.3	26
Parenteral nutrition	94	26.6	25	54.2	13	45.8	11
Peritoneal dialysis	96	78.1	75	31.9	22	68.1	47
Anticoagulant IV therapy	91	87.9	80	81.4	57	18.6	13
IV chemotherapy	90	35.6	32	74.1	20	25.9	7
Hemodialysis	95	15.8	15	0	0	100.0	15
Sleep apnea monitoring	94	12.8	12	40.0	4	60.0	6
Monitoring of diabetic patients	90	8.9	8	42.9	3	57.1	4
Cardiac monitoring	94	3.2	3	50.0	1	50.0	1
Hypertension monitoring	93	2.2	2	100.0	2	0	0
Fetal monitoring	94	0	0	0	0	0	0

* Percentages have been calculated by using, as the denominator, the number of CLSCs who responded (R) for each item.

† Percentages have been calculated by using, as the denominator, the number of CLSCs providing direct and indirect care. The sum of the Ns of "direct" and "indirect care" does not equal the N of "ever delivered" due to missing data.

CLSCs were asked to identify the number of patients they had followed in fiscal year 1998-99 for each of the four selected technologies. Table 3 indicates the number of CLSCs who gave figures (several CLSCs do not use/have access to patient information systems) and the number of patients who received services at home and on site (ambulatory services). There were important variations from one CLSC to another in the number of patients receiving IV therapy and oxygen therapy, which cannot be entirely explained by population density. About the same average number of patients received IV therapy at the CLSC as at home. To our knowledge, the provision of ambulatory IV therapy services was never proposed by the MSSS, although CLSCs doing so are potentially able to provide services to more patients. The number of patients receiving parenteral nutrition and dialysis services at home from CLSC staff was low (varying from 1 to 20 patients).

TABLE 3

Number of CLSC patients, 1998-1999

TECHNOLOGY	AMBULATORY SERVICES					HOME SERVICES				
	R	Mean	Min	Max	S.D.	R	Mean	Min	Max	S. D
IV therapy	50	41.52	2	300	59.03	73	41.47	1	300	55.75
Oxygen therapy	17	63.82	1	180	59.66	58	52.76	1	275	57.96
Parenteral nutrition	-	-	-	-	-	11	1.91	1	5	1.22
Peritoneal dialysis	7	3.57	1	10	3.1	39	4.23	1	20	4.02

S. D. = Standard deviation

The majority of respondents felt that their number of patients had increased since 1996 for IV therapy and oxygen therapy, while more than half indicated that the number of patients on parenteral nutrition or peritoneal dialysis was stable (see Table 4). Based on interviews conducted with managers of CLSC home care programs, the "decreasing after an increase" response item was added to the questionnaire to reflect a situation that was thought to be prevalent for IV therapy. Such an inverse "U" curve may have been seen after some hospitals stopped referring patients to CLSCs, due to a lack of trust in CLSC services or a decision by the hospital to provide home care. This situation was confirmed by 13.6% of respondents.

TABLE 4

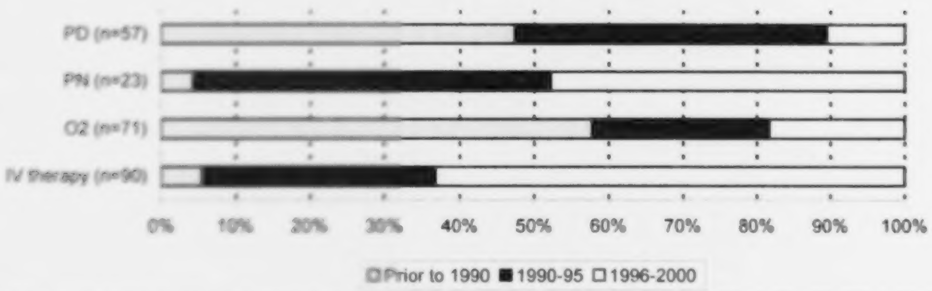
Perceived trends in the number of patients since 1996

TECHNOLOGY		STABLE		INCREASED		DECR. AFTER AN INCREASE		DECREASED		OTHER	
	R	N	%	N	%	N	%	N	%	N	%
IV therapy	88	9	10.2	63	71.6	12	13.6	4	4.5	0	0
Oxygen therapy	66	10	15.2	55	83.3	0	0	0	0	1	1.5
Parenteral nutrition	51	30	58.8	16	31.4	2	3.9	2	3.9	1	2
Dialysis	25	15	60	6	24	1	4	1	4	2	8

Figure 3 indicates the period during which CLSCs started to use each of the four selected technologies. IV therapy had been introduced recently for more than half of the respondents, which coincides more or less with the intensification of the *"virage ambulatoire"*. Oxygen therapy (O_2) was introduced prior to 1990 in half of the CLSCs providing these services. Parenteral nutrition (PN) was introduced more recently, while most CLSCs offering dialysis services (PD) were doing so prior to 1990.

FIGURE 3

First year of introduction of technologies by CLSCs



Note: The number of respondents for each technology is noted in brackets.

3.4 BARRIERS TO THE INTEGRATION OF TECHNOLOGY IN CLSCs HOME CARE PROGRAMS

Figure 4 shows the proportion of CLSCs who provided from 1 to 4 home care technologies. This represents the number of CLSCs that declared having been involved in the direct or indirect provision of services.

There are a number of factors that may explain why CLSCs are providing, or not, technology-enhanced home care. Figure 5 indicates the percentage of respondents who believed a factor was "limiting, very limiting or extremely limiting" (*"restreignant, très ou extrêmement restreignant"*) to their provision of home care. The factors have been sorted, placing the most limiting ones at the extreme right of the figure. As expected, the importance of each item varied according to the specific technology. The largest variations were associated with parenteral nutrition which can be explained by the fact that a close collaboration with hospitals is necessary for CLSCs to be involved in this type of service ("hospital staff attitude" and "proximity of specialized centres" holding a special budget can be seen as important facilitating factors. Overall, the "proximity of specialized centres", the "number of potential clients" in the CLSC territory, the level of "financial resources", the "complexity" of the interventions, and the "number of referrals" were perceived as the most important barriers. The factors most frequently perceived as facilitating the involvement of CLSCs in technology-enhanced home care were "CLSC priorities", "staff attitude", "expertise", and "access to equipment".

FIGURE 4

Proportion of CLSCs providing technology-enhanced home care services

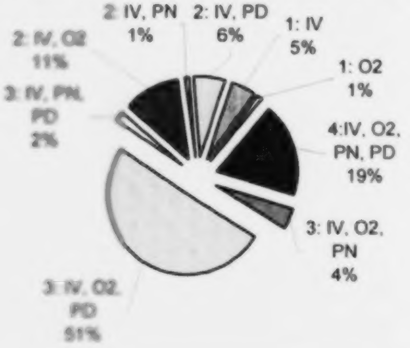
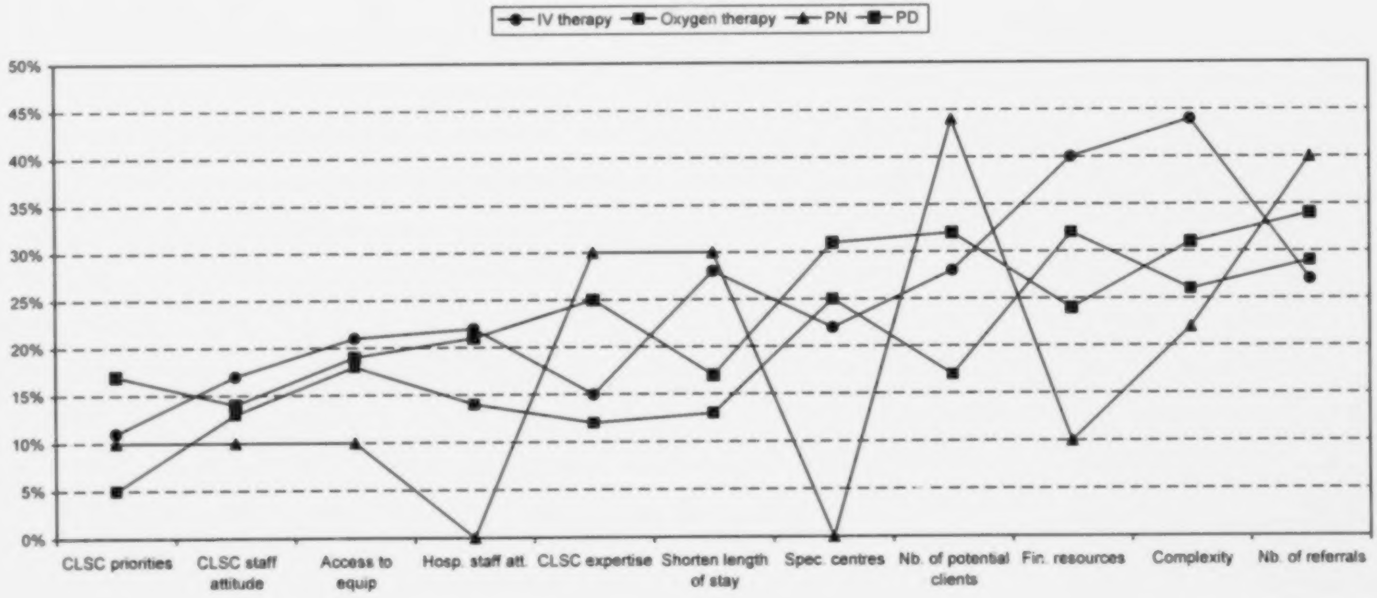


FIGURE 5

Perceived barriers to the integration of technology-enhanced home care



Note: The three levels of the scale were "limiting," "very limiting", and "extremely limiting".

3.5 ORGANIZATIONAL ISSUES AND RELATIONSHIPS WITH HOSPITALS

This section summarizes the findings pertaining to patient charges, sources of information/evidence, training, and relationships with hospitals.

In Québec, patients do not normally pay anything to obtain or use disposables (e.g. dressings, tubes, etc.) required by a range of home care services. Hospitals in most regions are required to "lend" equipment to local CLSCs free of charge. Despite these arrangements, anecdotal evidence suggests that access to equipment is not uniform across the province. Thus, survey respondents were asked whether patients had to pay to obtain certain items or services. Table 5 indicates that patients on oxygen therapy were often asked to pay for the purchase, rental, or refill of oxygen cylinders, or for delivery charges.

Table 6 shows the frequency at which different sources of information/evidence about technology-enhanced home care were used by CLSCs. Hospitals and manufacturers and/or suppliers of equipment were by far the most frequent sources while *régies régionales* (now called *agences de développement de réseaux locaux de services de santé et de services sociaux*), scientific journals, AETMIS, and Web sites were used to a very li-mited extent. A similar question sought to identify the sources of training for CLSC home care staff (see Table 7). Here again, manufacturers and hospitals were important sources, while the most frequent form was training by fellow staff members from the CLSC. In consideration of the wider responsibilities CLSC staff have had to assume under the *"virage ambulatoire"*, one may wonder whether the current training strategies should be supplemented by formal training, grounded in high quality scientific evidence.

TABLE 5

Percentage of CLSCs indicating patients had to pay for these items

TECHNOLOGY	ACQUISITION OF EQUIPMENT	RENTAL OF EQUIPMENT	DELIVERY OF EQUIPMENT	ANTIBIOTICS, O_2, FEEDS OR DIALYSAT	OTHER
IV therapy	0	3	7	51	7
Oxygen therapy	14	49	18	63	34
Peritoneal dialysis	0	2	0	9	4
Parenteral nutrition	0	4	4	28	4

Note: Possible answer was either "yes" or "no".

TABLE 6

Sources of information used by CLSCs (%)

SOURCE	NEVER	OCCASIONALLY	OFTEN	VERY/ EXTREMELY OFTEN
Written material by hospitals	1	25	40	34
Written material by manufacturers	3	31	27	39
Written material by professional bodies	0	34	41	25
Representatives	2	38	37	23
Written material by *régies régionales* (now *agences de développement de réseaux locaux de services de santé et de services sociaux*)	22	41	21	16
Scientific journals	7	64	21	9
Meetings and trade exhibitions	13	61	21	5
AETMIS	43	42	12	2
Web sites	62	33	3	3

Note: Two levels of the scale ("very often" and "extremely often") were grouped together.

TABLE 7

Sources of training for CLSC staff (%)

SOURCE	NEVER	OCCASIONALLY	OFTEN	VERY/EXTREMELY OFTEN
Your CLSC	2	24	45	29
Vendors /manufacturers	2	42	35	21
Hospitals	6	63	20	11
Biomedical engineering firms	45	26	14	6
Professional organizations	42	44	6	3
Other CLSCs	44	47	4	1

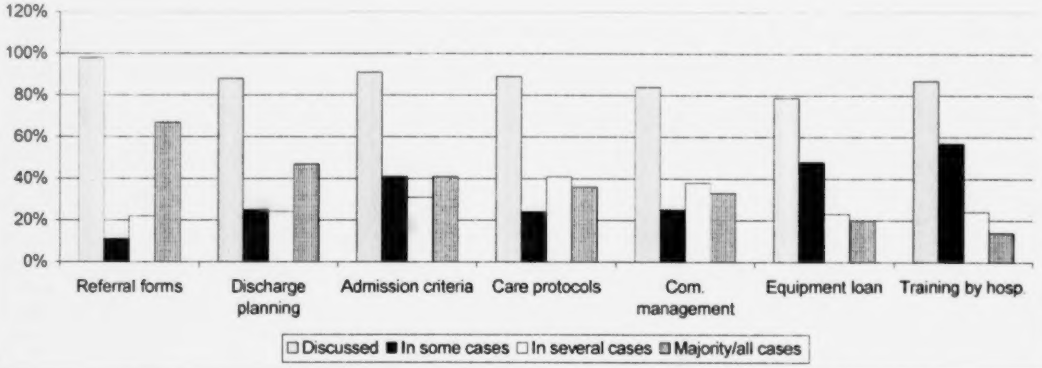
Note: Two levels of the scale ("very often" and "extremely often") were grouped together.

Finally, the survey sought to understand the nature and quality of the relationships that CLSCs had established with referring hospitals. Since the quality of the relationships may be related to the number of hospitals with whom a CLSC deals, a question addressed the number of "regular collaborating hospitals". Three different patterns could be identified: 1) 24% of CLSCs had only one collaborating hospital; 2) 49% had between two and four; and 3) 27% had between five and eleven. The CLSCs in the first group were mainly from remote regions (e.g. Abitibi, Gaspésie–Îles-de-la-Madeleine), those in the second group represented rural and semi-urban regions (e.g. Estrie, Lanaudière), and those in the third group were from metropolitan regions (Montreal, Quebec City). This finding implies that diverse arrangements in terms of staff training, discharge planning, care protocols, and coordination might be developed in response to these three organizational contexts. For instance, those CLSCs dealing with more than five partners may need to establish formal mechanisms of communication and coordination, whereas those dealing with a single hospital may rely on informal mechanisms (personal contacts, for example, may be effective and manageable). The implementation of care protocols is also likely to be easier in remote regions than in metropolitan areas, where each hospital may want the CLSC staff to adhere to its own protocol of care.

Respondents were asked to indicate whether particular topics had been discussed with their collaborating hospitals (see Figure 6, 1st bar from the left), and whether these discussions had developed into formal agreements (2nd, 3rd and 4th bars). Figure 6 shows that these topics had been discussed by a wide majority of CLSCs (more than 75% in each case). Formal agreements most often concerned referral forms, the planning of patient discharge, and admission criteria. Issues related to clinical care protocols, management of CLSC-hospital communication ("Com. management"), equipment loan, and training by hospitals were less often settled through formal agreements.

FIGURE 6

Topics discussed and frequency of formal agreements



Note: Two levels of the scale ("in a majority of cases" and "in all cases") were grouped together.

Due to challenges presented by the *"virage ambulatoire"*, one might expect difficulties or tension in the relationships between CLSCs and hospitals generated by an increased need to share information and coordinate their interventions. A significant portion of CLSCs (26%) indicated that patients were "often" referred by hospitals inappropriately, while 65% responded that such a situation happened "occasionally".

Most respondents were satisfied with several aspects of hospital relationships. Table 8 shows the percentage of respondents who agreed with the item listed in the left column. Overall, it appeared that CLSCs and hospitals had established positive relationships—especially from the nursing staff and home care program management perspectives—although the level of understanding of each other's respective constraints was limited.

TABLE 8

Aspects defining the relationships between CLSCs and hospitals (% endorsed)

	SOME CASES	SEVERAL CASES	MAJORITY/ ALL CASES
Communication between nurses are excellent	3	24	72
Hospitals respect CLSC's admission criteria	3	33	64
Hospitals transmit adequate information	13	51	36
The level of confidence from hospital physicians is high	17	47	36
Hospitals respect delays fixed by the CLSC	19	45	34
Respective constraints are understood	21	50	28

Note: Two levels of the scale ("in a majority of cases" and "in all cases") were grouped together.

3.6 DISCUSSION

The above results clarify some of the organizational issues affecting the use of technology in home care. As mentioned in the introduction to this report, new technologies are often seen as a major source of change in the delivery of home care. These technologies are often assumed to be easy to use, reliable, and user-friendly. They are also supposed to facilitate early discharge of patients, and to reduce hospitalization rates. Yet little is known about the extent to which CLSCs are using such technologies. Box 3 summarizes key findings from the survey.

BOX 3

Key findings from the CLSC survey

- The survey indicates that CLSCs were most commonly involved in IV therapy and oxygen therapy.
- For both of these technologies, the number of patients per CLSC varied greatly and the average number of patients per CLSC could be high enough to justify consolidating staff expertise (mean: 40 to50 patients/year per CLSC).
- CLSC involvement in parenteral nutrition and peritoneal dialysis was found to be less common. The former is certainly limited by the total number of patients requiring such services in Québec and the latter by the proximity of specialized hospital-based services. For these two interventions, the number of patients per CLSC was very low (mean: 1.9 to 4.3 patients/year per CLSC). This finding raises questions about what might be a reasonable threshold to guarantee sufficient exposure for the staff to remain knowledgeable and competent in providing such services.
- Nineteen percent of CLSCs had provided four technologies, whereas 57% had been involved in the provision of three technologies.
- One-third of CLSCs had been involved in the provision of IV chemotherapy, a finding that should trigger further investigation.
- Despite its high visibility and the potential benefits it carries, home telecare has not reached the doors of Québec CLSCs. One may expect this figure to change drastically in the next years as the Federal government is investing heavily in this area across the country, and since several start-up companies are establishing pilot projects with hospitals and CLSCs.
- The importance of facilitating and constraining factors varied across technologies. Overall, the proximity of specialized centres, the number of clients in the CLSC territory, the level of financial resources, the complexity of the interventions, and the number of referrals were perceived as the most important barriers.
- The factors that were perceived most frequently as facilitating were CLSC priorities, staff attitude, expertise, and access to equipment.
- The two major sources of information about technology-enhanced home care were hospitals and the written material provided by vendors/manufacturers.
- The relationships between hospitals and CLSCs were seen as generally positive by CLSCs, especially at the nursing level.
- The most frequent formal agreements concerned referral forms, the planning of patient discharge and admission criteria.

For comparative purposes, results of a study by Kaye and Davitt [1998] merit consideration. Table 9 shows the most frequently used technologies and services by a sample of American home health care agencies (the services also studied with the Québec survey are highlighted). This study indicated that of a sub-sample of US hospice care providers (e.g. those specializing in care for terminally ill patients), 76.1% offered technology-enhanced services. The table indicates that the US home health care agencies that participated in the study were involved more often than Québec CLSCs in sleep apnea monitoring (62.4% vs. 12.8%), chemotherapy (57.4% vs. 35.6%), and cardiac telemetry (16.3% vs. 3.2%). As the parenteral nutrition category included enteral nutrition, we cannot draw any comparison with Québec CLSCs for this technology. Finally, US home health care agencies were less involved in renal dialysis care than CLSCs (7.1% vs. 78.1%), which may be explained by a different prevalence of peritoneal dialysis use in the US and/or by differences in the organization of services. Overall, the US study was limited by the sample type (which included for-profit agencies) and by a very low response rate (30%).

TABLE 9

Technology-enhanced services/equipment provided by American home health care agencies (N=140)

SERVICE/EQUIPMENT PROVIDED	FREQUENCY	PERCENT (%)
Incontinence care	131	93.6
Pressure sore care	130	92.9
Ostomy care	127	91.4
Tracheostomy care	119	85.0
Pain control/palliative measure	121	85.2
Oxygen	120	85.7
Antibiotics (infusion)	116	82.9
Parenteral/enteral nutrition or hydration	118	82.5
Apnea monitoring	88	62.4
Chemotherapy infusion	81	57.4
Ventilator care	68	47.9
Transcutaneous electronic nerve stimulation	72	51.1
Electronic monitoring & recording of vital signs	54	38.8
Personal emergency response systems	52	37.7
Blood component infusion	36	25.7
Cardiac telemetry	22	16.3
Bone growth stimulation	12	8.7
Renal dialysis	10	7.1
Self-instruction computer	5	3.6
Telecommunications/closed circuit TV	5	3.7
Robotics	2	1.5

Source: Kaye and Davitt, 1998, p. 12.

Beyond the question of the appropriate levels of utilization of technology, lie substantial organizational issues as well. Historically, CLSCs have been responsible for home care and other primary care services. The execution of their mandate has always been tightly linked to community approaches, emphasizing preventive services and educational interventions that aim to respond to local needs. With the *"virage ambulatoire"*, their mandate appears to be shifting towards post-acute, more specialized care. The provision of home IV therapy is an archetype of such a shift: the explicit goal is to shorten hospital length of stay, using CLSC staff to provide and monitor therapy at the patient's home. However, one may question whether the current CLSC organizational design and expertise could be better supported to accommodate the *"virage ambulatoire"*.

According to Kaye and Davitt [1998; p. 16], home health care agencies should be concerned about their ability to provide certain services: "agencies may be providing service to all types of patients regardless of diagnoses and treatment modality. This triggers questions regarding quality of service, training needs of staff, and the capacity of agencies to respond to all care needs and to provide all types of treatments". Two frequent admission criteria are the patient's ability to learn and handle his/her own care and the availability of a caregiver. Since home care patients' abilities can deteriorate over time, the caregiver's role is especially crucial. It has been suggested that home care agency staff should thus assess carefully the patients' and the caregivers' learning potential, as well as their physical and psychosocial status (e.g. levels of depression, anxiety).

Although it is repeatedly stressed that the availability of technology will facilitate an increased provision of home care, the knowledge, skills and know-how that home care staff will have to possess are less often described. The CLSC survey results makes one wonder about the neutrality and the scientific basis of the information home care providers have access to, and are transmitting to patients and caregivers. Knowing that vendors/manufacturers are also very active in the training of hospital staff, the level and quality of training required by home care providers should be examined. Overall, if the *"virage ambulatoire"* is to succeed in enhancing the effectiveness and quality of home care, a clear staff training policy is required—based on research evidence about technical and clinical issues, and encompassing ethical and psychosocial considerations specific to the provision of technology-enhanced home care.

4 ISSUES IN ORGANIZATION AND DELIVERY

The use of technology at home implies major, visible changes in the way care has been provided over the last 50 years in industrialized countries. These changes have an impact on professional care providers, patients, caregivers, families, and society at large. Introducing more sophisticated technologies into the home setting has created new types of patients, new treatment possibilities, new roles and responsibilities for providers and caregivers, new ethical dilemmas, and new areas of accountability. This part of the report is an attempt to clarify and summarize issues that are often entangled both in the literature and in practice. For instance, ethical issues often carry legal implications, organizational procedures are required to deal with new legal requirements, and new technological means imply social transformations. Chapter 4 presents the findings of an international literature review, identifying the aspects of technology-enhanced home care which should be taken into account in the development of Québec home care policy.

4.1 ORGANIZATIONAL DIMENSIONS

Organizational dimensions of technology-enhanced home care are intimately linked to the characteristics of the home care delivery model (e.g. eligibility, access to services, skill mix, etc.) and to the particular needs of patients in terms of care, technology, and support. The discussion here is limited to home care delivery models, coordination between providers, communication with patients and caregivers, and adaptations to the home environment. A few cost-effectiveness issues will also be discussed, albeit briefly since the literature on cost-effectiveness is complex and deserves to be analyzed in greater depth in a separate report. Readers interested in cost-effectiveness issues may consult a series of HSURC reports [2000, 1996a,1996b], the more recent series of studies chaired by Hollander [2002], titled the National Evaluation of the Cost-effectiveness of Home Care, the study by the University of Toronto Home Care Evaluation and Research Centre (HCERC) [Coyte, 2002], a Cochrane systematic review [Parkes and Shepperd, 2000], a UK-based HTA agency systematic review [Elkan et al., 2000], a thorough economic evaluation [Dougherty et al., 1998], and a systematic review [Soderstrom et al., 1999].

4.1.1 Cost-effectiveness

The cost-effectiveness of home care is sometimes taken for granted; since hospital costs are so high, any alternative appears less costly at first glance. For instance, the Romanow [2002, p. 171] report underscores that "there is growing evidence that investing in home care can save money while improving care and the quality of life for people who would otherwise be hospitalized or institutionalized in long-term care facilities." However, detailed economic evaluations of home care reveal that there are broader types of costs that should be recognized, among which are the costs of hospital re-admissions, private home care, and lost income of caregivers [Soderstrom et al., 1999]. With this perspective, Gelijns and Rosenberg [1994, p. 42] argued that "empirical analyses that *unpack* the forces underlying technological change and its relationship to health care costs are urgently needed to strengthen the basis for future policy making." These authors stressed that three mechanisms of action contribute to the overall levels of utilization and costs: 1) variations in intensity of use (e.g. the "technological imperative"); 2) introduction of new or modified technologies; and 3) expansion of indications for use (i.e. more individuals are treated or tested). We may expect these three mechanisms to operate in the case of home care development: it is possible that a specific technology will be used when a "wait-and-see" approach would be as effective and perhaps safer, when a different technology could be implemented, or when the technology is not medically required. In fact, much complexity arises when one wishes to know whether specific home care interventions are cost-effective compared to traditional care methods. To illustrate some of the challenges, two studies and a commentary are summarized in detail below.

Soderstrom et al. [1999] conducted a systematic review of the evidence regarding the effects of acute home care on the health of patients and caregivers, and on the social costs of managing the patient's health conditions. Fourteen studies (inclusion criteria: publication between 1975 and early 1998, adult population, use of a control group) were first identified from MEDLINE and HEALTHSTAR databases. Only four of these studies met the internal validity criteria specified by the authors (i.e. patients were eligible for home care; comparable patients in the home care and hospital groups; adequate study size; appropriate analytical techniques, health measures, and costing methods). Five specific health conditions/interventions were evaluated in these four studies: hip fracture, hip replacement, chronic obstructive pulmonary disease (COPD), hysterectomy, and knee replacement. Social costs were defined as the sum of three factors: 1) hospital costs savings due to shorter length of stay; 2) the added public and private costs of the home care program and other health services used; and 3) the positive or negative change in non-health system costs borne by patients and caregivers (e.g. baby-sitting, transportation). Except for hip fracture where small positive effects were found, home care had no effect on patients' or caregivers' health compared with hospital care. Social costs under home care were unaffected for hip and knee replacement and higher for COPD and hysterectomy, while no such costs were reported for hip fracture. Overall, effects on health system costs (i.e. excluding non-health system costs) were mixed: cost savings were observed for hip fracture whereas costs were higher for hip and knee replacement. The authors thus concluded that the effects on social and health system costs vary with the condition, and that the limited evidence reviewed suggested that acute home care does not produce notable difference in health outcomes.

There can be cases where a specific home care intervention is considered appropriate from a public policy perspective, despite an overall increase in costs. For instance, Dougherty et al. [1998] examined the health and cost effects of using home care to treat newly-diagnosed Type I diabetic children, rather than traditional hospital care. Sixty-three children were randomized into two groups and followed for 24 months. Children in the home care group (n=32) were discharged from hospital after their metabolic condition stabilized, and insulin adjustments and teaching were done in their homes by a trained nurse. Social costs (i.e. net change in costs for the health system and parents) were $48 higher under home care. According to the authors, "the increased cost of health care services with home care ($768) was largely offset by parental cost savings ($720)." This evaluation focused on pediatric home care, an area where parental involvement as caregivers is usually high, and where the benefits of discharging children from hospital are obvious (e.g. to reduce the risk of nosocomial infections). The results of this evaluation suggest that criteria other than strict cost-effectiveness should be used to decide whether to implement a home care program or not; among others, these criteria include feasibility, quality of care, and comprehensiveness of the program.

A commentary on home care published in the fall 2000 issue of Healthcare Papers by Thompson [2000, p. 61] sheds light on how decisions to provide different types of home care services (or not) can be grounded on evidence about their cost-effectiveness. The author suggests that evidence about effectiveness of home care can be examined adequately only by distinguishing the goals of diverse home care interventions. The goal of "curative" care is "to restore functioning that has been temporarily lost, or limit the loss of functioning caused by sudden insult to good health." If clinical outcomes of care are as good at home as in hospital, then the policy issue is one of cost-minimization, or cost-substitution. If the outcomes are better in one of these locations of care, then the issue is one of cost-effectiveness: "Do the better outcomes justify the additional cost, compared to other opportunities to use those resources?" The goal of "preventive" care is to prevent deterioration in client functioning. According to Thompson [2000, p. 62], "the burden of proof is heavier for preventive home care, because establishing equal outcomes is not sufficient, as preventive home care is not a substitute, but an add-on." The goal of "supportive" care is to "maintain the client at as high a level of independent living as possible, for as long as possible". This goal can be achieved through home care, nursing homes, and assisted living. Caregivers' health can also be maintained through supportive housing, institutional respite care, and support groups. Thus, to identify whether supportive care is cost-effective, client and caregiver outcomes should be compared for each alternative.

Thompson argues that several studies support the conclusion that outcomes of **curative** home care are as good or better than hospital care. This author stresses that recent economic evalu-ations have highlighted the need to achieve substitution for demonstrating cost-effectiveness; otherwise, there are no cost savings. Substituting home care for hospital care requires effective discharge planning and close integration between hospital and home care providers. An HSURC [1996a] report argued that several US randomized trials failed to demonstrate the cost-effectiveness of **supportive** home care in the 1980s, since a majority of clients in supportive home care demonstration projects were in fact receiving preventive care, for which the alternative was no care. According to Weissert [1985; Weissert et al., 1997, cited in Thompson, 2000], supportive home care can be cost-effective only with true single entry and accurate targeting of clients at risk of nursing home admission. Integration is required between nursing homes and home care programs so that priority clients are admitted first. According to Thompson, **preventive** home care has not yet been clearly and unequivocally proven cost-effective. In the cases where better outcomes have been identified, this has concerned high-risk populations of elderly after discharge from the hospital [HSURC, 1996b]. Integration between hospitals and CLSCs is again the key here. Nonetheless, a more recent study by HSURC [2000] cast doubts on the cost-effectiveness of preventive home care. Retrospective analysis of administrative records indicated that seniors receiving preventive home care were 50% more likely to lose their independence or die than those not receiving such service. The average total health services costs for preventive home care recipients were triple those for non-recipients. Residents of seniors' housing were 63% less likely to lose their independence and 40% less likely to die, and had about the same total health services costs as non-residents. Seniors' housing thus appears more effective and less costly than preventive home care, perhaps due to increased socialization and decreased use of other services. However, the authors themselves acknowledged several limitations in this study (for example, the selection bias inherent to the use of administrative data to compare groups, the use of crude outcome measures, and the fact that costs were limited to those borne by the health system). Policy-makers should wait until replications of these results are published and augmented with clinical data before acting upon such findings.

In summary, the extent to which home care interventions are cost-effective is not clear. However, this is not a sufficient reason to cut home care services. According to Béland and Bergman [2000], a high proportion of those with health needs do not have sufficient access to home care and continuing care. For instance, a study by Trahan et al. [2000, cited in Béland and Bergman, 2000] showed that CLSCs were providing nursing care at home to 31.2% of day surgery patients and to 85% of post-hospitalized patients, while homemaking services were delivered almost exclusively by families: CLSCs provided homemaking services to 3.7% of day surgery patients and to 18.8% of post-hospitalized patients. This suggests that home care services may not be deployed to the fullest extent in Québec, and that families are providing a significant portion of care and support. Thus, well-designed evaluations are needed to clarify the cost-effectiveness of specific home care interventions and how costs are being shifted from the health system to the patients and their families.

4.1.2 Integrated health care delivery models

The 1990s saw the emergence of integrated health care delivery systems in North America and Western Europe, assuming diverse forms while aiming to improve the quality of care through patient-centered coordination among care providers. The majority of home care is provided by nurses, while family physicians are more involved in patient follow-up. The objectives of nursing care delivery systems are to assess the patient, identify the nursing needs, and provide the nursing care until the patient is discharged from the program [Lyon, 1993]. An integrated home care delivery system facilitates a closer collaboration between nurses, physicians, other professionals, and home helpers. The purpose of client-centered case management is to assist the patient through a complex, often fragmented and confusing health care system, while system-centered case management serves rationing and priority-setting functions as well. Traditional models of home care are likely to be altered by integrated service delivery systems, in which home care has closer links with other levels of care, such as hospitals or nursing homes, in a care continuum [Handy, 1995].

Continuity of care is paramount in such systems. Based on a survey of children whose routine source of care was a community health clinic, O'Malley and Forrest [1996] found that continuity of care was associated with a two-fold increase in the odds of receiving age-appropriate preventive services. Based on interviews with patients, another study found that the factors associated with a continuous care relationship were patient familiarity with the physician, physician knowledge of the patient, patient satisfaction with care received, and patient confidence in the physician [Gabel et al., 1993]. Personal attributes of the physician, friendship with the physician, ease of communication, and professional growth of the physician were also associated with this relationship. The availability of the physician and the location of practice were reasons to start consulting a physician.

Integrated service delivery systems are also thought to be cost-effective compared to traditional delivery models. A Randomized Control Trial (RCT) demonstrated that an integrated model of service delivery, based on interdisciplinary care-management and blended modalities of service, enhanced quality of life and was a cost-effective method of providing care for terminally ill AIDS patients at home [Huba et al., 1998]. According to a cohort study [Forrest and Starfield, 1996], the use of an identified primary care source during the first visit (first-contact care) was associated with reductions in ambulatory episode-of-care expenditures of over 50%.

Nonetheless, Okun [1995] has argued that technology-enhanced home care program development has largely preceded research on safety and effectiveness. Outcomes research in this area has been given the challenge of determining the effects of home care attributable to such diverse factors as the illness itself, the home setting, professional care received, and social support. For instance, in a retrospective analysis of discharges for congestive heart failure and total hip replacement recorded by six home health agencies (in New Hampshire, USA), O'Sullivan and Volicer [1997] observed that variability in likelihood of meeting care goals is much better predicted by patient characteristics (e.g. diagnosis, age, functional limitations, prognosis, rehabilitation potential, presence of an able and willing caregiver) than by utilization of home care services.

Access to services is another important issue when considering home care delivery models. Through an analysis of three American databases containing renal dialysis patients, Kendix [1995] found a negative association between the number of facilities per square mile and the probability of provision of home services. In Québec, hospitals are increasingly providing ambulatory care services [AHQ, 1997] and specific home care programs (e.g. IV therapy, parenteral nutrition). Each hospital seeks to implement a model of care that remains flexible, as technology is changing rapidly. One might expect CLSCs to be less involved in home care when such services are offered by local hospitals, since hospitals control patient flow (Lehoux et al., 2001b]. However, if a specific service is to be offered jointly by a hospital and a CLSC, communication and coordination between organizations will be crucial. In our prevailing health care system, there are few organizational or financial incentives for consolidating collaboration between CLSCs and hospitals. For ex-ample, there is no specific budget to hire liaison agents, and no information system that can be used to transfer patient information from hospitals to CLSCs, or vice-versa [Lehoux et al., 2001b]. Low levels of mutual understanding will tend to impede the development of solid collaboration.

4.1.3 Physician involvement in home care

Since the implementation of Medicare in Canada, physicians have not been largely involved in the provision of home care. As highlighted by an issue of the Canadian Family Physician [Laberge et al., 2000, p. 2022-9], several disincentives limit the number of house calls by physicians. Eaton [2000], in the editorial of this journal issue, lists ten reasons and/or preconceptions about why doctors do not make house calls. First, this could be related to a lack of role models for younger physicians due to a shortage of family physicians in several regions (this shortage forcing them to decrease the provision of house calls in favor of other medical services). Second, diagnostic support in the home environment is limited, and physicians may be less comfortable performing examinations and establishing diagnoses without the tools that are easily available in clinics or hospitals. Third, some patients can be inconsiderate to physicians by not respecting schedules or by being excessively demanding. Fourth, physicians may be worried about lack of hygiene and concerned about spreading disease to themselves or others. Fifth, getting to a patient's house (e.g., finding the way) can be difficult and frustrating. Sixth, physicians may be put off by having to attend lengthy meetings of interdisciplinary teams common in home care. Seventh, fear of assault and litigation may also limit physicians making house calls. Eighth, some physicians may feel overwhelmed by the complexity of geriatric care (in particular, end-of-life care) and fear intense family entanglements. Ninth, house calls may be perceived as an inefficient use of time. Tenth, financial compensation for making house calls is insufficient, given that several Canadian government agencies do not pay for travel time.

Some of these arguments may seem weak or unfounded. Nonetheless, physicians are given the choice of providing or not providing home care, and their decision may depend on all sorts of objective and subjective considerations which should be recognized by home care managers and policy-makers. A recent survey, administered to family physicians in the Québec city region (response rate: 487/696=70%), confirmed that physician involvement in home care was low: Laberge et al. [2000] found that 58.1% of their respondents were making house calls to a clientele consisting mainly of elderly patients (87.6%). Forty-two percent of these physicians saw fewer than five patients per week, close to one-third (31%) spent 2 hours or less per week on house calls, and close to two-thirds (64%) devoted 15 to 30 minutes to these visits. Only 22% of their patients were also receiving home care services from a CLSC. Finally, a minority of physicians (19.5%) had participated in multidisciplinary meetings at the CLSC. In summary, although home care patients can see their family physicians when they need medical advice, the overall role of physicians in home care remains limited, as does their collaboration with CLSCs.

4.1.4 Working in home care

Several observers have described the differences between nursing responsibilities in home care and typical hospital-based nursing duties. Brown [1996] has stressed that a new generation of advanced practice nurses is required to provide cost-effective, quality home care. Nurses with skills in case management, outcomes management, research and education, and program development are needed. In Québec, several nursing positions in hospitals have been transferred to CLSCs under labor force redeployment measures. This relocation may have represented a profound clinical and professional change. A US survey revealed that nurses' job satisfaction did not vary according to the care delivery model, and that organizational culture was more important than the type of unit and specialization in explaining job satisfaction [Kangas et al., 1999]. Krause and Crowell [1995] argued that nurses newly employed in specialized home care facilities face seven transitional stressors: differences in health care settings, adaptation to a corporate environment, decrease in peer support and contact, responsibility for new treatments, increased independence and isolation, problem solving without direct patient contact, and personal and professional self-esteem issues. Indeed, hospital nurses who are used to being able to consult their peers whenever they need assistance must assume broader responsibility when they do home visits [Lehoux et al., 2001b].

Kaye and Davitt [1998] examined the organizational characteristics of a sample of American hospice and non-hospice (regular) health care agencies (n=154). A hospice was defined as "an interdisciplinary program of palliative care and supportive services that addresses the physical, spiritual, social, and economic needs of terminally ill patients and their families" [p. 2]. Hospice care usually emphasizes the following: pain and symptom control; attention to the psychological needs of both patients and families; use of interdisciplinary care teams; and continuity of care throughout the dying process and through bereavement. Frequently offered services include: morphine pumps; subcutaneous infusion; continuous intraspinal morphine infusion; palliative chemotherapy; blood product infusion; artificial nutrition and hydration; respiratory care (oxygen, tracheostomy, ventilators); and the increasing use of personal emergency response systems. As previously mentioned in Chapter 3, the response rate to this survey was low (30%). Forty-six point seven percent of the agencies surveyed provided hospice services, among which 56.3% were not-for-profit, 28.2% were for-profit and 15.5% were public. The primary sources of revenue for both hospice and non-hospice agencies were the Medicare and Medicaid programs (for up to 86% of respondents). On average, hospice agencies provided more home visits per year (mean=40,679.9) than non-hospices (33,691.2) and served more patients (777.7 vs. 624.8). Hospice agencies employed more part-time employees (71.7% vs. 30.3% on average), while the percentage of full-time staff was roughly equal (35.9% vs. 35.6%). Hospices employed more field staff (92.5% vs. 56.3%) and more office staff (18.8% vs. 11.5%) than non-hospice providers. Kaye and Davitt stress that dependence on full-time staff may be a source of logistical difficulty when replacement staff is needed (due to vacations, illness). Part-time workers may be employed intentionally by hospice agencies since the provision of services is psychologically and physically intense and stressful in this setting. However, from the patient's perspective, full-time staff employment status may reduce turnover and variations in which staff member sees each patient, improving continuity of care.

4.1.5 Provider-patient communication

Home care is comprised of multiple dimensions, among which are culture and family relationships. Home care nurses are challenged by cultural differences, language barriers, loss of control, family dynamics, unfamiliar environments, and new technology [Petit de Mange, 1998]. McNeal [1998] has also observed that the "culturologically" competent nurse should be able to obtain value-free cultural information and use this information sensitively in the development of care plans. It has been shown that patient-focused family physicians, compared to disease-focused specialists, order fewer tests and procedures, sustain a partnership with patients, lead to less costly health care, and handle greater diagnostic uncertainty [Rosser, 1996]. A questionnaire survey of patients and physicians revealed that participatory decision-making is influenced by physicians' background, training, practice volume, and professional autonomy [Kaplan et al., 1996]. Cost-containment strategies that reduce time with patients may result in sub-optimal patient outcomes since decision-making style is related to patient satisfaction and loyalty to the physician.

4.1.6 Home adaptations and equipment design

Technologies used in home settings have not necessarily been designed in consideration of the features of a 'typical' home environment. Moreover, homes may differ substantially in terms of available space (including refrigerated storage room), access to a phone, number of stairs, number of rooms, heating and ventilation systems, reliability of electrical supply, proximity of services, etc. The design of particular devices may also be a source of concern. Some technologies are less user-friendly than others, which may explain low levels of compliance. Designers of technology used at home should incorporate consideration of user-friendliness; if not from the viewpoint of patients themselves, this concept should be explored with home care providers. Design judgment will always be crucial in the development of medical devices. Established principles for the design of medical equipment, such as those of the Association for the Advancement of Medical Instrumentation in the USA, are a good starting point. Designers need to meet with users (both professionals and patients), understand their needs, working environments, and stresses, and foresee what could go wrong [Wiklund, 1995].

Patients with chronic illness must often modify their homes in order to accommodate a piece of medical equipment (e.g. oxygen concentrators, dialysis cycling machines). Some adaptations are effective and safe, while others may prove harmful or risky. Brown and Mulley [1997] had suggested that health professionals visiting elderly people at home should look for home-made aids with a view to promoting safety and identifying solutions that may help others. Some patients may also tolerate living in awkward situations (e.g., patients on oxygen therapy using only one floor of the house because only one set of tubes could be connected to the concentrator), either for fear of appearing too demanding of the public health system or due to a lack of awareness of possible solutions. User satisfaction with home care is rarely assessed formally, and when it is, assessment does not always include items related to the home environment. Thus, caution is advised when interpreting studies reporting high levels of user satisfaction. Brooker [1997] has pointed out that structured interviews elicit more reliable forms of feedback from elderly patient groups.

The home is a dynamic concept, as private houses, apartment buildings, and seniors' housing are being constructed differently, involving new individual and collective features (e.g. services, parks, recreational areas). According to Kaye and Davitt [1995a], technology will be more widely available to the functionally-impaired, community-based elderly population in the future. Home environments will become more automated; the disabled elderly will be able to use remote controls to modify environmental features (e.g. doors, windows, kitchen appliances, etc.). Home health care providers may encourage elderly clients to assume greater involvement in their own health maintenance as home environments are designed to maximize functional independence.

4.2 SOCIAL DIMENSIONS

Social dimensions in the use of technology at home refer to the capacity of the patients and their relatives to maintain (or resume after a sickness episode) satisfying relationships (conjugal life, friendships), engage in leisure activities, raise a family, carry out social roles, be employed and earn an income, and live without discrimination. Illness—and chronic illness in particular—can seriously affect a person's social capacity. Yet, the use of technology can pose an additional burden on social activities. For instance, the frequency at which it should be used, the level of the patient's dependency on its use, the anxiety caused by its use, the physical constraints it may impose, its visibility, and the stigma that may be attached to its use, are all factors likely to affect either the patient's breadth of social activities or his/her compliance to the regimen of care.

4.2.1 Impact on caregivers

In the 1960s, the mechanical ventilator was one of the first pieces of specialized equipment to enter homes in USA and Canada. Harrison and Mitchell [1961, cited in Okun, 1995, p. 42] studied the social and psychological burden associated with the use of this equipment. Nineteen percent of polio survivors experienced severe to total disruption in family integrity. The authors concluded that the "success of the home program and the extent to which the patient resumes his former role in society are based primarily on psychosocial factors rather than on the extent of the patient's physical disability and medical problem". Parents of technology-dependent children complain of difficult schedules, sleep disruption, loss of privacy, and limited social lives. Exhaustion, guilt, and a sense of endlessness were found in a study of parents caring for technology-dependent children [Kohrman, 1992, cited in Okun, 1995]. Because parenteral nutrition, for example, can become a means of extraordinary life support over time, perceptions of futility may arise in parents with severely ill children. Young adults on Total Parenteral Nutrition (TPN) experience depression, fear of dependence on machinery, financial hardship, and distorted body image [Okun, 1995]. Thus, it is not easy to balance the positive psychological effects of home care against its associated burden and risks (i.e., mechanical failures, infections, and complications are potentially fatal).

More subtle are other consequences of introducing technology into the intimate, private lives of patients. As sociologists have demonstrated how technology transforms human relationships, expectations, and daily routines in institutional settings, one would expect that specialized home care will have similar effects in the home environment [Akrich, 1995]. Dying at home, for instance, may appear attractive to both patients and family members at first glance, although in practice it is rarely simple. For instance, "agonal breathing, incontinence of urine and feces, and fear of impeding death are facts about the dying process that have been largely hidden from Americans in an era when 80 percent of people die in hospitals and nursing homes" [Arras and Dubler, 1995, p. 3]. Some impacts on caregivers are ambiguous, posing problems of meaning and identity for individuals. As the sociologist Gubrium has put it, home care is "biographical work", challenging people to redefine their relationships with others, as well as their self-image. For instance, the natural role of family members, especially parents, is often to reassure, protect, and safeguard from harm; however, in their role as providers of care and maintainers of equipment, they must sometimes inflict serious pain and suffering on the person who requires medical care [Arras and Dubler, 1995, p. 6]. Caregivers must learn a great deal about technology and develop manual skills (for example, unclogging catheters, preparing parenteral nutrition solutions, or trouble-shooting defective equipment). Such tasks have been the exclusive domain of highly-trained personnel in the past.

In addition, some patients and their families may feel isolated or even abandoned at home; physicians do not necessarily make home visits, and have no financial incentives to engage in long phone conversations with patients. Moreover, providing long distance care is less professionally rewarding to most clinicians [Pfister, 1995]. Many insurance plans in the US deny physician reimbursement for time spent on the phone with families or managing a home care plan [Larkin, 1992, cited in Arras and Dubler, 1995]. This distance creates a dual effect on the patient-physician relationship. On the one hand, because physicians are remote from the site of care, they are largely dependent on family members to obtain the correct information. On the other hand, family members are dependent on physicians for a comprehensive elucidation of the benefits and risks of a given treatment.

In summary, technology-enhanced home care involves a complex social phenomenon. The availability of specialized home care can improve "life for many while threatening to erode for others the conditions that tend to foster important social goods and opportunities—such as nurturing home life with its intimacy, privacy, and freedom from the bureaucratic and rationalized trappings of institutions, as well as full economic and social opportunities for women" [Arras and Dubler, 1995, p. 4]. For Arras and Dubler, the central questions thus becomes: "What kind of homes and families do we want our society to foster, and at what price?" As a corollary, Arras and Dubler suggests that an increased sensitivity to the ways in which the notion of home is transformed by the emergence of technology-enhanced home care may push society to explore other solutions, such as reforming existing structures to make them more home-like", rather than transforming home into annexes of medical institutions. In the meantime, careful selection of patients and caregivers, complemented by appropriate training and support of caregivers, should be central to all home care programs.

4.2.2 Who are the caregivers?

According to Health Canada [Dumont-Lemasson et al., 1999, p. 1], "many people provide care without any sense of obligation, while others may view it as a duty, as a sacrifice, or as a necessity if formal structures are no longer available". Informal care may be provided to a spouse, a child, an elderly parent, a friend, or a neighbour. Care giving tasks may fall into two categories: 1) instrumental activities (e.g. housework, meals, transportation); and 2) personal care (e.g. bathing, dressing, toileting). According to Schachter and Holland [1995, p. 92], "family caregivers have suddenly become paramount in home care". Caregivers are instructed in the management of technology and are expected to administer treatments on a rigid schedule. Successful palliative home care also requires an evaluation of the family by the physician or nurse, including dimensions such as motivation, psychological strengths and weaknesses, expectations, and economic and social resources.

At a societal level, ethical concerns are raised by the distribution of the care-giving role among family members. It is reasonable to state that caregivers are more often women (although exceptions include men caring for wives with cancer or Alzheimer's disease and for homosexual partners with AIDS, among other cases) [van den Boom, 1991, and Monette, 1988, cited in Arras and Dubler, 1995, p. 8]. Wives, daughters, and mothers are often seen as 'good at this sort of thing', and their wages (if they have to take leave from employment) are lowered in most cases. Although some women may perceive care giving positively (for example, as an opportunity for reciprocity or gratitude), others may have such a role imposed on them through our widely unquestioned social norms. Furthermore, there is an increasing number of single working mothers who have to support both older parents and children with their sole income.

Given that the number of seniors has doubled over the past 25 years, one might also expect that both caregivers and patients are increasingly elderly [Cranswick, 1997]. Using data from the 1996 General Social Survey in which 13,000 Canadians from the ten provinces were interviewed regarding community and social support, Health Canada has attempted to draw a picture of the Canadian caregiver's profile: overall, more Canadian women were providing informal care to people with long-term health problems than men. In the age group 25 to 44 years, 14% of women were providing care compared to 10% of men. A larger proportion of caregivers belonged to the age group 45 to 64 years (19% of women and 11% of men) and were caring for elderly parents [Cranswick, 1997].

4.2.3 Measuring and addressing caregiver burden

The measurement of caregiver burden poses several methodological challenges. The most common scales examine mental health (e.g. depression, distress), physical health (e.g. illness, illness-related symptoms), or general burden of care giving (e.g. emotional, social, and financial strain). Scales may include self-report measures, interviews, or clinical assessments. In particular, the different scales available are not necessarily well-suited for caregivers of demented elderly [HSURC, 1996b].

Financial problems are a strong predictor of caregiver stress. Yet, the HSURC [1996a] review pointed out that the indirect or time cost of the caregiver was rarely included in economic evaluations of home care. The authors stressed that indirect costs are multiple and sometimes difficult to measure. Private insurance may not cover many expenses related to home care. Parents of a technology-dependent child, who are able to continue working, may remain "wage slaves" to their employers [Okun, 1995, p. 43]: for instance, they may accept staying in a less desirable position in order to retain health insurance premiums.

Technical support (home aid) is often available to families who are only able to pay for services on an occasional basis. The problem is that such support is not always efficiently (nor coherently) organized, and therefore does not provide a sense of security [Arras and Dubler, 1995]. A choice between hospital and home may not even exist for many families. According to Arras and Dubler, physicians and hospital administrators tend to disqualify families from assuming decision-making roles, seeing any conflicting views as "conflicts of interest". In contrast to the medical model, authority and responsibilities are widely dispersed and typically shared in the home setting.

Programs that increase informal support and opportunities for activities with friends and family may alleviate caregiver burden to some extent. Respite care provides periodic relief to caregivers by arranging placement of elderly patients into hospitals or personal care homes [HSURC, 1996a]. Providing information to caregivers may also help reduce their burden (e.g. about available community-based services or resources). Support groups offer emotional encouragement and can help caregivers develop specific coping skills [Schachter and Holland, 1995]. HSURC [1996b, p. 24] found research evidence to support the assertion that "respite care should be available as a *preventive* service, not after a crisis has developed; respite will be more effective if applied frequently and for a sufficient period of time; there is a need to define and target high needs groups; knowledge and education are important in decreasing caregiver burden; and lack of supportive services may actually increase caregiver burden over time".

4.2.4 Situations where home care alters social relations

According to Schachter and Holland [1995], the benefits of palliative home care do outweigh the liabilities, which can be minimized by responding to the family's needs with appropriate interventions. In patients dying of cancer, pain is present in 60 to 90 percent of cases. The distress for caregivers is high as they fear giving too much medication, over-sedating the person or hastening death, or giving too little, leaving the patient in pain. For patients with a history of drug abuse, families and physicians may resist the use of pain medication as they are suspicious of the reported pain and fearful of the patient's drug dependency [McCabe et al., 1995]. Caregivers who are assisting a dying relative at home have more opportunity to say last goodbyes, and may feel fewer regrets ("I did all that I could do"). Yet, children may often be excluded from discussions of the ill patient at home and lack information about what is happening, thus "the family secret of terminal illness is experienced by them as something terrible they may have caused" [Schachter and Holland, 1995, p. 99]. They may feel guilty, frightened and isolated from the rest of the family; acting out, anger, and a seeming lack of consideration for the ill person may then lead to severe criticism of their behavior.

HIV infection/AIDS patients often feel pressured because of disease progression to disclose their stigmatized diagnosis to family and friends, with accompanying fears of rejection, anxiety, and sadness. Also, "prior life choices may have led many patients to distance themselves from their families" [McCabe et al., 1995, p. 85]. Further isolation and loneliness may result from poor communication about the HIV/AIDS diagnosis. When the patient becomes debilitated, social isolation can limit the home care options. HIV/AIDS patients, who are often young, may consider their life to be less valuable because they drain their social and financial resources while remaining unable to become productive again. As the illness progresses, risks, stress, and complexity generally increase. Additional problems relate to making a will, repairing estranged relationships in some cases, arranging foster care or adoption for children, prearranging a funeral, and ensuring that benefits go to an intimate partner or spouse. Tremendous relief may be experienced by patients in completing such tasks, and an increased ability to share their thoughts about the dying process.

4.3 ETHICAL ISSUES

Arras and Dubler [1995] had highlighted the hyper-medicalization of the home—and the extension of the medical domain to the private sphere—as a key ethical issue. These authors have also stressed that profiteering by manufacturers and the failure of regulators and industry to assess quality and efficacy of equipment are ethical issues that need to be addressed as well. In fact, "sorely neglected in this rush for profits, however, [has been] any seeming awareness, let alone a systematic analysis, of the possible ethical impacts of these new developments on the patient, the family, and involved caregivers; the notion of 'home' in our society; and the equitable extension of these new benefits." This section summarizes the most common ethical issues raised by the use of technology at home, concerning either the patient or the caregiver.

4.3.1 General definitions

For Kohrman [1995], as individuals, as professionals, and as a society, we are unclear about the value of the modern transformation of human beings through health care. For instance, a technology-dependent child evokes a chimeric entity, a combination of human and technical attributes that confuses people. It is terrifying to see a child on a ventilator struggle as the caregiver inserts a tracheotomy tube into a secretion-filled trachea. According to Kohrman, it is impossible to construct an ethical system for something about which we have a limited understanding, and that involves people about whom we know very little: the technology-dependent patient and his/her providers and caregivers. Interestingly, most individuals in modern industrialized societies are technology-dependent in a certain sense: power failures dramatically reveal the far-reaching scope of such dependency. For Kohrman, however, there are two very different types of dependence: one that that is more or less optional (e.g. using telecommunications), and one that is more or less mandatory (e.g. using a life-sustaining device).

Kohrman suggests distinguishing between two meanings of the word 'value'. First, values can be used to define a hierarchy of preferences or choices that guide social decision-making and political actions. For instance, since independence, physical beauty, the ability to compete, and individualism are so valued in Western modern societies, the disabled and the technology-dependent individuals tends to be depreciated. Values held by physicians and providers also have an impact on the technology-dependent patients. Preferences for cure, willingness to fight and get better, and evidence of improvement can be seen as conflicting with chronically ill patients. The second meaning of 'value' can be that of cost and worth. Technology-dependent individuals "are not more expensive than weapons or cosmetics or some of the other things we as a country and individuals spend large sums of money on, but they are expensive in the range of ordinary medical and social endeavors" [Kohrman, 1995, p. 60]. The moral worth to our society of keeping these individuals alive and optimally supported should also be explored as a social responsibility.

According to Arras and Dubler [1995], the decision to implement high-tech home care should be both medically and ethically indicated. He emphasizes two areas of concerns. First, **communication and consent**: patients and family members should be aware of the psychological, cultural, and social barriers that can hinder effective home care (e.g. relating to self-dignity, trustworthiness, management of bodily contacts, ability to cope with stress, etc.). They must also be fully informed about the kind of technical challenges they will face, the likely stresses and strains of providing care, the likelihood of missing work days, the out-of-pocket costs, and the loss of privacy due to the presence of frequent professional visitors. The second area concerns **justice**: one should recognize that others besides the patient have legitimate needs and that just decisions might not always favor individual patients. Caregivers who learn to manipulate equipment may live in a constant (perhaps silent) state of panic. Societal expectations for women to conform to stereotypical roles tend to constrain the decision to be a caregiver. Overall, because the high-tech industry is concerned with profit and hospitals are seeking to cut their operation costs, "neither can be trusted to give a well-balanced presentation" of the burdens and benefits of home care [Arras and Dubler, 1995, p. 20]. After autonomy and justice, the other two overarching ethical principles are beneficence and non-maleficience [Heitman, 1998]. These require that only care that is proven (or clinically thought to be) safe and beneficial be provided, and that clinical guidelines ensuring quality of care be implemented.

Thus, for each patient case, a unique set of variables needs to be examined so as to define the realistic limits of care giving at home: family relationships, the type and duration of care, and the objectives of the treatment. Since the care needs of the patient are most likely to evolve over time and may impose increasing burden on the caregivers, it appears ethically important to offer home care on a trial basis, and periodically re-evaluate the situation. Home care agencies market a service, but tend to make their profits selling devices, drugs, and intravenous fluids [Pfister, 1995]. Why would there be more public resources for technology-enhanced home care when basic needs of many patients for non-medical community supports remain unmet? Increased regulation of home care seems both necessary and inevitable for Arras and Dubler [1995]. However, a fair, democratic procedure for deciding whether and how to ration home services is yet to be established. Reliable information is lacking and difficult decisions remain.

4.3.2 Comfort vs. life-sustaining treatments

In certain instances (e.g. for a patient with Alzheimer's disease, or a ventilator-dependant child), it is reasonable to argue that the major ethical issue is not the high-tech component, but rather the chronic nature and the intensity of the care provided, as well as the emotional costs to the caregivers [Arras and Dubler, 1995]. For instance, the use of nutritional-support technology for elderly has been controversial for some years [Pousada, 1995]. Although its use with active and physiologically 'young' elderly with limited or potentially treatable diseases remains uncontested, its use for oral nutrition with severely demented or comatose patients who have progressed to a permanent incapacity raises several questions. Reasons to support feeding in the latter case include: perception of food as an ordinary and not unusual measure; the minimally invasive nature of a nasogastric tube; fear of litigation for having 'starved' a patient to death; and an ethical mandate to prevent death under all circumstances. According to Pousada, the practice of providing hydration without feeding should not be encouraged, because it can result in enough water, sugar, and salt being provided as to ensure a slow death from starvation (months), rather than a quicker and less painful death from dehydration (less than two weeks). See also the discussions of concrete examples in a recent book by Saint-Arnaud [1999].

4.3.3 Capacity issues

Kaye and Davitt [1998] examined the degree to which a sample of American home health care agencies (n=154) dealt with different patient capacity issues when delivering high-tech services to elderly. Their study examined, among other things, the degree to which agencies were confronted with legal and ethical issues (table 10); the extent to which agencies were equipped to respond to these issues; and the formal mechanisms established to address them.

Almost two-thirds of the hospice providers (65.7%) and non-hospice providers (69.2%) in this study had established policies on life-sustaining treatment decisions. Only 39.7% of hospice agencies had policies on patient decision-making capacity. Hospice and non-hospice agencies used similar methods to inform patients and encourage participation (e.g. providing explanations upon entry into the program, actively seeking feedback and input). Thirty-two point four percent of respondents felt that patients were "very informed" and 46.5% were "informed" about legal and ethical issues.

The above study also suggested that the legal and ethical dimensions were surfacing with an increased frequency. Despite the enactment of the Patient Self-Determination Act (PSDA) in USA in 1991, it is surprising that 31% of the agencies in this survey did not have advance directives (e.g. do-not-resuscitate and living will measures) and treatment decisions policy. The PSDA requires health care providers and home health agencies to: "1) maintain written policies and procedures regarding state law on advance directives; 2) inform patients upon admission of their rights under state law to direct medical treatment and to execute an advance directive; 3) inform patients of agency policy on advance directives; 4) document the existence of an advance directive in the medical chart; and 5) educate agency staff and the community about advance directives" [Kaye and Davitt, 1998, p. 18]. In the same vein, the low number of hospice providers (less than half) with a patient decision-making capacity policy is questionable. This means that staff or agencies are left to their own discretion on how to handle ethical dilemmas. As suggested by research evidence [Emmanuel, 1991, cited in Kaye and Davitt, 1998, p. 18], patients often wait for providers to initiate discussions concerning decision-making competence, living wills, or do-not-resuscitate measures.

TABLE 10

Ethical and legal issues faced by American home health care agencies

ISSUES	MEAN (a)	S.D.
Use of living wills	2.1	1.0
Use of durable powers of attorney for health care	1.8	0.9
Decisions by patients to forego life-sustaining treatment	1.6	1.0
Interaction with guardians (public or private)	1.6	0.8
Conflicts between family's wishes and patient's wishes	1.6	0.8
Decisions determining patient competence	1.5	0.9
Decisions by families to forego life-sustaining treatment	1.4	1.0
Patient's right to privacy and confidentiality	1.3	1.1
Limited guardianships/conservatorships	1.1	0.8
Surrogate decision-making/substituted judgment	0.9	0.9
Problems with obtaining informed consent	0.8	0.7
Conflicts between surrogate's (guardian or durable power of attorney) and patient's wishes	0.8	0.8
Summary Index Score	**1.4**	**0.5**

Source: Kaye and Davitt, 1998, p. 12.
Note: (a) Item, independent factor range 0-3 where: 0=never, 1=rarely, 2=sometimes, and 3=often.
S.D.: Standard Deviation

4.4 LEGAL ISSUES

Several factors suggest that more issues of legal liability in home care will arise [Kapp, 1995a]: home care is becoming increasingly high-tech (for patients who would have otherwise been institutionalized); patients are being discharged "quicker and sicker"; and coordinating care provided by various professionals is becoming more complex (making it more problematic to control legal risks). The literature we found is dominantly American and British, and does not necessarily focus on the legal issues raised by the use of technology at home. We nonetheless decided to summarize this literature because it does highlight issues that may grow in importance with the development of technology-enhanced home care, and may be currently underestimated in Québec. Indeed, the safe and appropriate use of technology at home depends on the level of skills and competence of both formal care providers and caregivers. In this section, we thus summarize the most salient legal issues by: 1) introducing the five general legal aspects suggested by Kapp [1995a]; 2) defining the caregivers' legal responsibilities; 3) describing in further detail the care providers' areas of accountability; 4) clarifying how home care staff competence can be seen as a legal requirement; 5) identifying risk management strategies; and 6) stressing the importance of thorough record keeping.

4.4.1 Overview: Five legal aspects

According to Kapp [1995a], the US context for home care includes extensive federal and state regulation (licensure laws on professionals and home care agencies), intended to promote and protect the health, safety, and welfare of patients.

There are also strong financial incentives for home care agencies to obtain voluntarily accreditation (e.g. from JCAHO, NHCC, CHAP). Although there is a high anxiety level among home care providers, few civil malpractice lawsuits have been launched on behalf of patients or against home care agencies or individual professionals [American Medical Association, 1991, cited in Kapp, 1995a]. Kapp discusses five legal aspects of home care in particular, described below.

First, one source of potential liability for home care agencies to patients is associated with a breach or violation of contract with patients (e.g. contractual liability). This may take the form of: 1) a violation of (implied or explicit) promises to patients regarding availability and quality of services in the agency's advertising materials; and 2) failure to fulfill explicit promises made to patients or their surrogates.

Second, an agency and its staff can be subject to lawsuits for negligence in patient care and deviation from acceptable professional standards causing injuries (e.g. tort liability). Assignment, supervision, and monitoring of professional and paraprofessional employees thus represent a "liability danger zone" in home care [Kapp, 1995a, p. 34]. One significant risk associated with the home care setting is for patient injury caused by inadequate communication amongst agency staff, or between the home care agency and other providers involved.

Third, sophisticated equipment used in home care may be the cause of problems and patient injury due to defects (e.g. product liability), incorrect installation, improper use by professionals, insufficient training and skills of caregivers, or mistakes by patients and caregivers. In the United States, the home care agency is considered, for legal purposes, to be acting as both a professional service provider and a seller of products. The agency is then accountable, on the one hand, for proper installation, supervision, and inspection of equipment and its operation, and, on the other hand, for adequate training of providers, patients and family members in the correct use of equipment.

Fourth, as home care agencies have legal duties due to their professional relationship with a given patient, the process by which they accept to provide care to patients should be scrutinized (e.g. acceptance, transfer, and discharge of patients). While an agency may not discriminate against patients based on irrelevant attributes (e.g. gender, race, religion), it may reject patients on the basis that the agency is unable to provide adequate quality care to him/her (e.g. a severely disabled person or one with complex intervention needs). In addition, an agency must have a clear policy for terminating a relationship (e.g. transfer to a nursing home) that protects a patient from being abandoned, without appropriate care, during a transition period.

Finally, under legal requirements that go beyond the health system, home care agencies may be sued (both civilly and criminally) if any of its staff commits client abuse, neglect, or mistreatment. They are also liable for the unauthorized release of sensitive patient-specific information.

4.4.2 Caregivers' legal responsibilities

In the home care setting, new roles are attributed to family members (or others adopting a caregiver's role) as they participate in the care giving process, involving legal implications [Kapp, 1995a]. The first aspect to consider relates to decision-making. Caregivers will participate, to varying degrees, in decision-making concerning patient care, whether the patient has the capacity to make his/her own decisions or not. A formal delegation of decision-making to others may occur for patients who are cognitively or mentally incapacitated. A non-relative may be appointed under the powers of attorney. Kapp observes that "usually, though, the transfer is silent, with the patient superficially acting as decision-maker but in reality relying completely on the family caregiver's opinion" [p. 37]. The "family decision-making hierarchy" often appears more clearly in the home care setting than in any other health care delivery site. The rest of the family may tend to agree with the member who lives with the patient and makes most of the decisions.

A second aspect that deserves legal (and ethical) attention is the support given to family members to act as fully as possible as caregivers. Instruction can take various forms, such as workbooks, checklists, and audiovisual materials. The home care agency must document the teaching process, and the caregivers' progress as well. The agency should monitor the family's performance and be ready to respond to any adverse alterations in the patient's health status. Professional licensure laws usually restrict the provision of health-related services such as giving medications and operating medical equipment to individuals duly certified. However, in home care practice, family members often do such activities. In general, they are neither empowered nor prohibited to do so by the State [Kapp, 1995a, p. 39].

A third aspect refers to decisions to limit treatment, which often involve caregivers. In the case of life-sustaining medical treatments, initiation, continuation, withholding or withdrawal pose legal and ethical dilemmas. "Living wills" and "do not" orders are one type of advance directives that can facilitate such decisions. The Patient Self-Determination Act passed by the US Congress in 1991 defines several procedural requirements for Medicare- and Medicaid-certified home care agencies. These are mandated to: "1) create written policies and procedures, consistent with state statutory and judicial law, regarding how they will handle advance directives; 2) provide written information to new patients or their surrogates regarding state law on advance directives and the provider's policy on implementing the state law; 3) document whether the patient has executed an advance directive; and 4) offer decision-capable patients the opportunity to voluntarily execute such a directive. However no patient may be coerced into taking this action" [Kapp, 1995a, p. 40].

4.4.3 Providers' areas of accountability

Formal care providers have generally four areas of accountability: 1) to the public, via criminal law; 2) to the patient, via civil law; 3) to the employer, via a contract of employment; and 4) to the profession (in UK, via the Scope of Professional Practice: United Kingdom Central Council for nursing, midwifery and health visiting [UKCC]) [Scales, 1996]. Criminal law seeks to establish guilt and determine punishment. Civil law seeks to establish accountability and award damages. Contracts of employment are reciprocal—both employer and employee must fulfill his/her part of the contract—and rely on grievance procedures. Misconduct charges, including ethical misconduct, are investigated by professional bodies and specific actions can be taken (e.g. banned or restricted practice).

When a patient or relative is dissatisfied with the care received from the care provider he/she can sue for negligence. Three criteria must then be fulfilled: 1) a duty of care must be proven between the health authority/individual professional and the patient; 2) a breach in the duty of care must be proven; and 3) there must be evidence of damage (e.g. psychological, physical, financial) caused by that breach [Scales, 1996]. Scales note that "whether it is the individual or the health authority that is sued will depend upon the quality of the policies, practices, and educational programs of the employer, as well as the performance of the individual." Such policies should be well-written, evidence-based, up-to-date, and fully implemented, so as to clearly define the correct course of action for providers. If this is not the case, the health authority may be blamed. In fact, vicarious liability refers to a situation where the employer (legally the 'master') takes the responsibility for the actions of an employee (legally the 'servant'; in this case, the care provider). The employer may choose not to support the employee when an employee breaches his/her contract and deviates from the policies of care. Care providers should acknowledge the limits in their own personal skills and take actions to remedy any gap in knowledge or skills (e.g. education, supervision). Policies should be regularly reviewed, be written as unambiguously as possible, but should also allow the application of clinical judgment. A policy which is too prescriptive may put a provider at risk when he/she deviates from its content.

4.4.4 Competence of care providers as a legal requirement

Legal liability and risks can be significantly reduced when competent clinical staff apply accepted standards of care [Friedman, 1997]. According to Scales [1996], failure to apply available research findings could be considered negligent if a civil action were brought against a care provider in the United Kingdom. For example, in order to administer IV therapy, nurses require sound knowledge in several specific areas, such as: legal, professional, and ethical issues; infection control; associated anatomy and physiology; fluid and electrolyte balance; pharmacology; management of blood and blood products; selection and management of disposable products for IV therapy; relevant mathematical calculations; methods of drug administration; and complications of treatment and their prevention [Scales, 1997, cited in Campbell and Lunn, 1997]. A survey by Wilkinson [1996, cited in Campbell and Lunn, 1997] revealed widespread dissatisfaction with levels of nurse training in IV cannulation and IV therapy in general. A critical mass of patients is required to maintain competency of staff. Indeed, "the opportunity to use skills regularly is of the utmost importance in developing and maintaining professional competence" [Campbell and Lunn, 1997, p. 1227].

The risks associated with blood and blood component home transfusion are not the same as those inherent to an acute care or ambulatory care setting [Friedman, 1997]. Four factors increase the risks: 1) only one staff member is on site if a patient problem arises; 2) the equipment and medication available to treat an acute problem are limited; 3) a laboratory is rarely available to analyze collected specimens; and 4) home care staff do not perform transfusions frequently. In the US, Licensed Practical Nurses (LPNs) may be prohibited in certain states from performing transfusions. Registered Nurses (RNs) are usually the primary professional responsible for providing home transfusions. In all cases, nurses should receive specific training in the following: the home care organization's policies and procedures; type and cross-match procedures; product procurement, transportation, and storage; in-home patient identification and product verification; blood-component administration procedures; recognition of adverse reactions and interventions; patient monitoring; and patient education and follow-up procedures.

4.4.5 End of life considerations

The role of physicians when patients die at home is ill-defined [Joy, 1998]. The physician's duties are oriented towards the bureaucratic and legal aspects of death. Providing valid information to a medical examiner is crucial. This means that physicians should visit a dying patient and execute a physical exam as soon as possible after death. Death certificate forms are in use across countries and regions, and clinicians should be shown how and when to complete these forms according to the prevailing legal framework. According to Kjervik and Badzek [1998], nurses can help patients and their families in understanding legal rights and responsibilities and encouraging them to act upon this knowledge. There are mechanisms that can be implemented by nurses such as advance directives and competency assessment. Nurses should be familiar with the criminal laws related to assisted suicide/euthanasia.

4.4.6 Record keeping

Appropriate record keeping is central in care provider accountability issues. A medical record should be an organized, clearly written synopsis of a patient's course of care from admission through discharge [Bowers and Adams, 1999]. As records should provide evidence of the care provider's actions, they should include: a comprehensive picture of care delivered and associated outcomes; relevant information about the condition of the patient at any given time and the measures taken to respond to identified needs; evidence that the practitioner's duty of care has been understood and honored; and documentation of the arrangements made for continuity of a patient's care [Scales, 1996]. For instance, it would be insufficient to describe a cannula site as 'satisfactory'. A more appropriate description would be: "the device appears intact; the entry site has no evidence of erythema, swelling or linkage." Furthermore, a situation should not be left unresolved at the end of a shift (e.g. prescription to be reviewed); the nurse must seek alternative advice before leaving if the doctor is unavailable.

As patients may wait several years to file a lawsuit in several American states, documentation that is written at the time an event occurs is often considered the best evidence [Bowers and Adams, 1999]. According to Bowers and Adams, records should: 1) be accurate; 2) be factual and objective (e.g. using measurements, patient's exact words); 3) be complete (i.e. each visit is documented) and precise (e.g. specific width denoted instead of 'small'); 4) use only approved and somewhat standardized abbreviations; 5) leave no doubt as to what actions or events occurred or did not occur; 6) not contain criticism against the patient, the caregiver, or other agency staff (this last information should be documented in the personnel record); 7) never use liquid paper correctors (a line should be drawn over an incorrect entry with initials and the date and time, while late entries should be cross-referenced to the original event with date and time); 8) document patient's directions about disclosure of medical information to relatives and update these whenever the patient changes his/her mind; and 9) reflect all attempts to contact physicians about changes observed in a patient's condition (name, reason for the call, response given).

4.4.7 Equipment liability

Carpenter et al. [1998] stressed that the survival of the American biomedical industry relied on three key elements: 1) the management of risks related to using products and risks associated with innovation; 2) the responsibilities of manufacturers, regulators, and users; and 3) the need for the informed consent of the user. These observations called for solid legal arrangements such as a formal mechanism to reduce the risks associated with biomedical products, and formal mechanisms to ensure informed consent by the patient. A paper by Cuthrell [1996] discusses the US Safe Medical Devices Act (SMDA) that was passed in the early 1990s. This Act aims to reduce the harm caused by unsafe devices or equipment failure, and requires immediate reporting of failures and withdrawal of unsafe products from the market. A home care nurse must become familiar with equipment function, appropriate settings, limitations, alarm settings, and intended use. Nurses in the US must also assume responsibility for the management and implementation of the SMDA (e.g. tracking process, management of operator errors, and reporting mechanisms). According to Fiesta [1999], providers and manufacturers have a joint responsibility to ensure patient safety. Risk management review should include training and monitoring employees on the use of new equipment.

4.4.8 Risk management

Nurses have responsibilities with respect to drug prescription, administration, and preparation in home care. According to UK standards, verbal and phone instructions to the patient/informal caregiver are unacceptable except in circumstances where an explicit policy defines how drugs should be prescribed [Scales, 1996]. With respect to drug preparation, a nurse should not use IV drugs that have not been prepared in her/his presence, and should discard unused infusion syringes before she/he ends the shift (see Box 4 for details). All infusions already in use must be labeled properly (with respect to content, date, time of preparation) so as to assist a nurse taking over the care of a given patient.

BOX 4

Guiding points to minimize risks with respect to administration of drugs

- Be certain of the identity of the patient;
- Be aware of the patient's current assessment and planned program of care;
- Pay due regard to the environment in which care is provided;
- Examine the prescription and information provided on containers in terms of safety;
- Question the physician or pharmacist when the information is illegible, ambiguous or incomplete, or when the dosage or route of administration appears improper;
- Refuse to administer the prescribed drugs whenever necessary;
- Refer patients to information leaflets about their medicine.

Source: Scales, 1996, p. 44.

4.5 STEPS FORWARD

In summary, organizational, social, ethical, and legal issues in home care are numerous and inherently inter-related. If a government chooses to promote home care as a cost-effective alternative to hospitalization, all of these issues should be acknowledged and addressed. Following the introduction of complex technology in family life, 'home' may not be home anymore, and ethical dilemmas and legal issues may soon surface. Home care implies a delegation of moral, clinical, and technical responsibilities to caregivers, whose health may, in turn, be affected by the care giving process. Box 5 thus summarizes what lessons can be learned from the above literature review for the development of Québec home care policy.

BOX 5

Key points for a Québec home care policy

- Home care, due to its very nature, is an area where services are at risk of fragmentation: several professionals will be involved with the patient and his/her family, pursuing their different professional goals, acting upon the available information, and behaving according to their particular clinical framework.
- A comprehensive home care policy should, therefore, include organizational incentives that promote trustworthy collaboration between organizations, between service providers, and between public health organizations and the informal/voluntary sector.
- A home care policy should also recognize the major role women play in informal care giving and sustain real choice by allowing them, for example, either to provide care without paying indirect costs (regarding career opportunities, health, etc.) or to choose not to play such a role.
- According to some authors (including Hébert et al. [1997]), caregiver work by men or women should be financially compensated. This avenue should be examined in further detail.
- The delivery of home care services, since the early 1990s, has become far too complex an enterprise to continue dealing with ethical issues on an ad hoc basis [Kapp, 1995a].
- Home care policy should be attuned to the ethical and legal considerations implied by specialized interventions; for example, the level of skills and understanding of complex procedures required is higher than for typical home care and requires that patients and caregivers be fully informed and supported accordingly.
- A formal risk management program should include liability insurance coverage, staff education, written policies (regularly updated), and an incident-reporting and follow-up system. Information about the clinical and legal risks involved in the provision of home care should be more routinely available.
- Since home care and medical equipment may be delivered by an array of employees from various agencies or organizations, it is critical to regularly conduct patients' and family members' assessments of the quality of the care and services they receive.
- Finally, the ethics committees which have been established in several university teaching hospitals in Québec should assist home care program staff in identifying and preparing for ethical challenges by pursuing policy formulation; staff, patient, family, and public education; and (concurrent or retrospective) case review.

5 DISCUSSION

Chapter 5 aims to bring together the issues raised in the previous parts. Recommendations are formulated around four central messages. As per the conceptual framework presented in the introduction, these four messages are cast at different levels. First, from a provincial policy perspective and with respect to technology-enhanced home care, there is an urgent need to articulate and redefine the roles of hospitals and CLSCs in the prevailing Québec home care delivery system. Second, it is clear that patients and caregivers need to be supported, informed, and equipped to perform the tasks and responsibilities involved in home care. This in turn implies that home care staff from hospital-based and community-based home care programs receive proper training to fulfill their 'knowledge transfer' role. Third, behind the promises of technology-enhanced home care lies the risk of overestimating its benefits and underestimating the necessary adaptations of the home environment, both in practical and philosophical terms. Fourth, there is a need for further research and open discussion to clarify questions about cost-effectiveness of different home care interventions. Before presenting our recommendations, key assumptions underpinning home care policies are discussed briefly below.

5.1 ASSUMPTIONS ABOUT THE PURPOSE OF HOME CARE

Baldock and Evers [1991, cited in Monk and Cox, 1995, p. 256] stressed that home care innovations are embedded in the "care culture" of each country, reflecting its traditions, dominant interests, and philosophy of service. For instance, the United Kingdom gives "more attention to the linkage between the formal and the informal or volunteer services sectors". Some home care policies assume that families are capable of taking a large part of the (if not the entire) responsibility for providing home care. Denmark has made pragmatic decisions to support home care—accepting the fact that the number of older persons living alone will grow while their networks of children and relatives will shrink— leading to a supply of home care that has "reached enviable and unmatched levels of adequacy."

More generally, Monk and Cox argue that the last two decades have witnessed a strong commitment to community-based home care for the elderly, largely propelled by two ideological positions that are prevalent in Western Europe. The first position, which centers on cost-effectiveness and cost-saving criteria, is concerned with the "policy of substitution": the replacement of costly services with less expensive ones which are as, or more, effective. For instance, the Netherlands governmental policy views home care as an alternative to institutional services in general, and informal support as preferable to community-organized services in particular. According to Monk and Cox, this policy position often assumes that self-care and primary prevention will grow in importance and ultimately contribute to a lower need for services among the aged. The second position refers to the "principle of normalization", made explicit in the Swedish Social Services Act of 1982, which stipulates that individuals should be assisted to enable them to live in their homes and continue leading their regular, independent existence. Such an aspiration is often accompanied by the promotion of social participation of the elderly persons in their local community as well as in the broader society. Although their initial results have been rather limited or at best ambiguous, home care policies in several industrialized countries have remained geared toward these two goals: substitution and normalization.

In Québec, normalization was an explicit component of the CLSCs' mandate from the very beginning, although the terminology has changed over the years (e.g. *maintien à domicile, soutien à domicile, soins à domicile*). The goal of substitution was introduced later, and emphasized by the *"virage ambulatoire"*. It is with the perspective of this latter goal that cost-effectiveness of home care is scrutinized. Nonetheless, technology-enhanced home care may contribute to fulfilling both goals: normalization, by allowing chronic patients to live more independently in their home environment, and substitution, by discharging patients earlier from the hospital or providing an alternate setting altogether. What remains unclear is the extent to which fulfilling these two goals implies (or not) that CLSCs are able to provide very different types of services (acute vs. chronic), within very different types of timeframes (short vs. long-term). The significance of this question stems from the level of expertise and familiarity that home care staff should maintain with the use of technology, and the organizational mechanisms that should be put in place to guarantee high clinical, ethical, social, and legal standards of care.

5.2 CAN THE QUÉBEC HOME CARE DELIVERY SYSTEM INTEGRATE TECHNOLOGY-ENHANCED HOME CARE SERVICES?

Several lessons can be drawn from this report. First, several technologies have not been introduced as part of a formal home care policy within the Québec health system; they have emerged as practical solutions and opportunities in diverse clinical fields—such as surgery, diagnostic techniques, and treatment of chronic and infectious diseases—on an ad hoc basis. The use of technology at home requires staff with varied professional and personal skills (i.e. self-discipline, ability to be autonomous, effective communication skills, knowledge of technology), the use of validated clinical protocols, the application of risk management principles, and compliance with ethical standards. It is thus reasonable to argue that the current Québec home care delivery system is not well-prepared for the introduction of technology-enhanced home care services because it was not designed to accommodate such innovations. A question then remains: could the current delivery system be modified to properly integrate technology? The answer is probably yes, although substantial changes are required given the above challenges.

Secondly, we must stress that the expression 'Québec home care delivery system' is incorrect as several different more or less organized programs exist, targeted at client groups with different care and assistance needs. CLSCs are an important player in this area but hospitals are also very active. CLSCs and hospitals have accumulated distinct forms of expertise that should be consolidated and shared. The use of technology at home is probably the best occasion for these two organizational cultures to start really working together. The CLSC survey results suggest that inter-organizational relationships (e.g. number of referring hospitals, availability of protocols, modalities of equipment acquisition) may differ substantially from one type of region to another (i.e. cosmopolitan, suburban, rural), which implies that different modes of collaboration between CLSCs and hospitals for using technology are likely to be effective [Lehoux et al., 2001a]. We shall know in a near future how the new *réseaux locaux de services* will meet this challenge.

Third, even though the decentralization process that occurred in the early 1990s gave enhanced budget allocations and priority-setting functions to the *régies régionales* (now *agences de développement de réseaux locaux de services de santé et de services sociaux*), the leadership for the development of home care amongst *agences* is not clear. A decentralized model, as found in England, Norway and Sweden, often claims that: 1) it fosters innovations and creative service solutions; 2) it makes services more responsive to local needs; 3) it promotes a patient-centered approach to services, thus avoiding constraints of uniformity; and 4) it enhances the consumer's freedom of choice [Monk and Cox, 1995]. However, in Oslo, Norway, as in other areas, a decentralized model has not prevented the "more educated and economically better off aged and disabled [to be] the ones who maximized and benefited from the use of public services" [p. 266]. Decentralization also raises the concern that a new administrative layer of government is added, absorbing budgetary resources that would otherwise be allocated to the direct provision of services. Thus, one may wonder whether 'regional' home care plans enable a coordinated, patient-centered response by CLSCs and hospitals.

Fourth, the home care industry is growing quickly and the province of Québec will soon have to deal with home care initiatives that are neither tightly connected to the public health care system (e.g. personal emergency response systems, over-the-counter diagnostic tests) nor based on an assessment of health population needs. Perry and Chu [1988], long-time advocates of health technology assessment, stressed that cost-containment strategies should redirect funds away from unnecessary and ineffective care and toward effective medical care. This argument cannot be overemphasized with respect to home care, as the marketing strategies of private companies often aim to appeal to the sense of security of elderly people and their relatives. In Québec, the role of the private sector in home care has yet to be defined.

In summary, if one of the goals of a Québec home care policy is to respond to technological changes in a humane manner (by offering high quality, timely, and closely-monitored home care services to the population), a global, integrated plan wherein each actor has a defined set of responsibilities and skills is needed. This overarching plan should rely on specific, well-defined policy measures and further research (defined below).

5.3 ADDRESSING THE "TECHNOLOGY AT HOME PROBLEM" IN QUÉBEC

In the introduction of this report, we defined four components of what can be viewed as the 'technology at home problem'. First, the development of an interface between community-based and specialized hospital-based home care appears increasingly crucial. New interventions are supposed to facilitate the provision of home care, but their use nonetheless implies a mix of specialized skills that are not always found in primary care settings. Second, a shift towards home care increases patients' and caregivers' responsibilities in many ways. This shift is accompanied by new organizational, social, ethical, and legal issues that should be addressed in a systematic and coherent fashion, with a clear provincial vision and strong regional leadership. Third, while several medical technologies have been historically designed to fit in the well-controlled, more predictable, strictly-monitored and sterile environment of the hospital, the patient's 'home' cannot be assumed to have similar characteristics. Specific attention must be paid to the unique features of patients' homes, so that it is possible to assess, over the long run, the true effectiveness and safety of home care interventions. Fourth, there is insufficient evidence about the costs and benefits of diverse home care interventions. The following section identifies avenues that should be explored in order to deal with the home care problem in Québec. Four primary recommendations are proposed, related to each of the four problems defined above. At the time of finalizing this report, we are aware of an important home care policy document is to be issued by the *Ministère de la Santé et des Services sociaux* (MSSS) in the coming months [Hervé Anctil, personal communication]. We believe that it should be possible to integrate our recommendations, which focus on the use of technology, in the course of implementing this overarching policy.

5.3.1 Recommendation 1: Establish innovative organizational mechanisms that support the delivery of coordinated home care

The survey on the use of technology in CLSCs revealed that their involvement in specialized home care was uneven and was often unknown to hospital home care teams [Law and Lehoux, 2001]. The number of patients visited by CLSCs, as well as their sources of information and training, raised quality of service issues. Even though their relationships with hospitals were perceived as generally positive, important organizational limits inherent to the current model of home care delivery have been reached. Effective coordination of services requires more than good relationships; specific inter-organizational mechanisms must be developed for sharing information, expertise, and care protocols. These mechanisms should involve frequent communication between providers, and between hospitals and CLSCs.

As shown throughout this report, technology-enhanced home care is not a straightforward solution to a major health system change such as the *"virage ambulatoire"*. This shift potentially gives a prominent role to community-based and primary care organizations, although human and financial resources have not allowed its full development. Nonetheless, interventions, such as home parenteral nutrition, may require a level of *expertise* found in secondary or even tertiary care organizations. An expert group, mandated by the MSSS, observed that several clinical and economic benefits are associated with ambulatory care [MSSS, 1998]. However, a critical mass of specialized expertise, patients, providers, and technologies is required. Dispersion of services is likely to increase patient mobility and reduce the overall effectiveness of services, while concentration of services generally reduces patient access. Kane [1995] argued that the fragmented financing and delivery systems of home care in the US lend themselves poorly to providing both high-tech and low-tech home services. Fragmentation between home care sectors interferes with continuity of care and diminishes accountability for quality. Moreover, as emphasized by the *Association des CLSC et des CHSLD* [1998], the strength of local organizations is pivotal for the success of the Québec reform, although the private sector should develop *within* the public system.

Thus, there is a discrepancy between what we are told technology can do as a key component in health care reforms and what its effective use implies in terms of users' skills and know-how. This discrepancy is not likely to be resolved by simply infusing more money in the system. A clear provincial strategy is required to ensure community-based home care programs and specialized hospital-based programs are coordinated at the regional level. It is not reasonable to expect providers from two different organizations (who are working under pressure and whose efficiency is assessed by different criteria) to voluntarily spend time trying to coordinate their actions in a way that will accommodate both groups. Although some larger hospitals may have been able to afford liaison agents within their own global budgets, this is not the case in several regions. Inter-organizational mechanisms (e.g. case managers, joint budgets, regional programs, shared information systems, practice guidelines) should be created, funded, and assessed. The difficulty lies with creating mechanisms than can be seen as legitimate by both CLSCs and hospitals, and that remain inclusive. A regional approach may prove effective, and should include mechanisms and tools that enable collaboration at both the administrative and clinical levels. Such collaboration will require broad multidisciplinary input.

Richards et al. [2000] had called for a major change in the skill mix of doctors and nurses in primary care. More equitable and less hierarchical models of multi-professional team working in primary care will have a greater chance of meeting the users' needs. For instance, Allen [1995] has suggested that as home health care grows, the use of biotechnology drugs in home settings will flourish and require specific handling, storage, and administration methods. Consequently, the role of pharmacists will necessarily increase. A pharmacist-managed therapeutic drug monitoring service could improve patient care, contain costs, and enhance education of pharmacy/medical students [Goode and Gums, 1993]. Shared decision-making and mutual respect should be core values, while ownership of care rests with the whole team rather than being confined to the medical profession. Stearns and Glasser [1993] had stressed that a paradigm shift is required in order to adapt medical practice to the challenges and opportunities of the new millennium. This author suggests that a paradigm for ambulatory medicine should combine elements of traditional medical care (e.g. etiology, history, physical examination, laboratory tests, and therapy) and elements of the ambulatory setting (e.g. continuity, context, health education, economics, and responsibility). Better understanding of the information needs of the health care teams should improve the development of appropriate information technology supporting the provision and management of home care [Tang et al., 1995].

5.3.2 Recommendation 2: Increase the level of support for patients and caregivers

With technology-enhanced home care, patients are expected to possess or quickly learn how to develop technical skills. Those involved in training patients/caregivers must be able to accommodate a range of physical, cognitive, linguistic, and psychological resources. Levels of education and income, as well as (conscious or unconscious) discriminatory behavior by professional care providers based on ethnicity or gender, are likely to affect the capacity of patients and caregivers to adequately use technology. From this perspective, there are inherent sociological risks to the use of technology at home. Social inequalities may be reinforced through the exclusion of some people from home care programs, or through having patients exposed to high-risk situations. To be socially appropriate and fair, the development of technology at home may have to rely on broad collective ethics that would clarify the kind of services to which underprivileged patients should have access. In fact, almost no research has been carried out on the knowledge, skills, and know-how required, from the patient's and caregiver's perspective, to adequately manipulate equipment. Appraisal of the patient's ability to execute technical procedures is done on an ad hoc basis by nurses or other therapists. Their work could be enhanced by research on what different patients can and cannot learn to do, as learning objectives could be set more appropriately. In addition, more research is needed on the user-friendliness of equipment. The higher the level of user-friendliness, the higher the level of patient well-being and compliance.

The caregivers' role is an extremely important component to consider in formulating a home care policy. So far, the contribution of caregivers to home care "has been by default, and not by design" [Parent and Anderson, 2000, p. 50]. In this perspective, the Romanow Commission [2002, p. 171] pushed the debate a little further by suggesting that a "new national program should be established through Employment Insurance to provide direct support to informal caregivers and allow them to spend the necessary time caring for their family members". According to the literature reviewed earlier, younger caregivers generally tend to be healthier. Employed caregivers often report lower burden as they are more able to hire someone to take charge of the 'hands-on' tasks. The socialization of women and men into specific gender roles results in women and men expressing their strain or burden, as well as in engaging in a caring relationship, in different ways. Women are more often responsible for 'hands-on' tasks such as bathing and dressing, while men more often perform activities such as banking. Husbands are thought to adopt a more instrumental approach to daily problems than wives [HSURC, 1996a]. Caregivers of individuals with Alzheimer's disease and other dementia disorders should receive particular attention in the context of an aging population. The Canadian Study of Health and Aging indicated that 8% of Canadians over 65 years, and 35% of those over 85, suffer from dementia [cited by HSURC,1996a]. The severity of the behavioral aspects of dementia disorders is positively associated with the anxiety/depression symptoms of the caregiver. Overall, caring for an elderly person with physical and/or mental dysfunction often results in health problems, including depressive symptoms, for the caregiver [HSURC, 1996a, p. 22]. This is why Parent and Anderson [2000, p. 50] suggest having the "[caregivers'] role and function clearly articulated through an informal caregiver policy that is incorporated within a broader human resource strategy and a home care system by design."

According to Hébert et al. [1997], assessment of patient autonomy is pivotal, CLSC services should be better organized (e.g. regarding time spent traveling and doing administrative tasks), and the benefits of the privatization of nursing homes are not evident. They also suggest that caregivers should be supported financially; otherwise, they are in a precarious situation, with their health and finances put at risk. An American analyst stressed a similar point by emphasizing that without sufficient uniform funding available throughout the US, large numbers of the frail elderly and disabled will remain dependent on friends, family, and privately-hired home care [Rosenzweig, 1995].

For several observers, the benefits of home care outweigh the risks and liabilities, which can in turn be minimized by addressing the family's needs (for information, health education, support, counseling, increased coverage, and comprehensiveness of programs) [Schachter and Holland, 1995]. To do so, providers need to be trained and rewarded in a way that recognizes the importance of training, supporting, and supervising the patients' and caregivers' learning curve. Nurses should aim to build trusting clinical relationships with patients and caregivers, and keep abreast of state-of-the-art treatments in the area of chronic care. Communication with patients and caregivers (including phone contact) should be a formal component of home care staff responsibilities. According to Krause and Crowell [1995], the introduction of technology-enhanced home care encourages high-level professionals to provide care, while information technology fosters delegation. Some technological advances encourage delegation to the patients themselves. Standards for ongoing supervision and periodic verification of competence must be established and all related aspects documented. For IV therapy patients, their learning curve may be limited, but their information needs are high. Nurses will thus have to spend more time with IV patients, who will not become as 'autonomous' as other patients. For chronic patients (e.g. those requiring parenteral nutrition or peritoneal dialysis), the learning process can be spread over a longer period, at the end of which patients become 'experts' themselves, and information needs will change as the disease evolves.

Furthermore, the elderly and children are two groups for whom an increased use of technology is observed in particular. They have specific needs in terms of education and moral support. Elderly persons may present specific challenges in terms of education, not only because of possible hearing, vision, or reading impairments, but also due to psychosocial factors such as dealing with depression, pain, and anxiety [Kaye and Davitt, 1995b]. Teaching self-care to elderly patients thus requires home care staff to develop creative strategies. Worcester [1987, cited in Kaye and Davitt, 1995b, p. 83] suggests the following: "1) allow the patient to control the pace of learning; 2) begin with what the patient knows, and clear up misconceptions; 3) use repetition; 4) check understanding before changing topics; 5) limit amount of material presented; 6) use large print, pictures, contrasting colors, magnifying aids; 7) use audio aids and eliminate background noise; 8) have the patient demonstrate by performing a task or repeating steps; and 9) provide adaptive devices to enhance patient abilities."

Lindeman [1992] stressed that one goal of nursing education is to prepare practitioners who can combine safe high-tech care with meaningful 'high touch' care (e.g. humane, empathic, patient-centered care). Nurses need to supplement their knowledge base in nursing interventions with additional training in ethics, health law, and technology assessment. In fact, a new generation of advanced practice nurses is required to provide cost-effective, quality care: nurses with skills in case management, outcomes management, research and education, and program development [Brown, 1996]. This new generation of nurses should also be aware of the means by which patients' needs and preferences can be elicited. Appropriate and acceptable services can only be developed by integrating users' views into decisions about health services [Joulle, 1993]. Home care potentially expands individual choice but only if public policy shifts extend the definitions of social rights: the rights and welfare of caregivers should thus be taken into account. In addition, patients' and caregivers' views cannot be substituted or adequately represented by those of purchasers or providers. According to Kelson [1996], methods of consumer involvement should be both strengthened and used more widely in policy-making. Progress is needed on the following: development of norms of good practice; development of organizational structures allowing for the evaluation of initiatives; and dissemination of evaluations for refining models of good practice. The development of consumer involvement in policy-making, although generally well-received by providers and managers, needs to be supported by systematic organizational initiatives (e.g. staff training, increased resources, reallocation of tasks) [Lupton and Hall, 1993].

5.3.3 Recommendation 3: Revisit the medicalization of home

It may be an opportune moment to pause and consider the rationale for the rapid development of technology-enhanced home care. Parent and Anderson [2000] underlined that insufficient research has been conducted to explore the full range of possibilities for supportive living arrangements. Similarly, more research is needed to examine patient preferences and situations where they would rather choose institutional care. According to Kaye and Davitt [1995b], the expansion of home care services in the US is "clearly driven by health care economics, and related changes in market demographics." The US Prospective Payment System (PPS) has contributed to the expansion of the market for home care services, and of technology-enhanced home care in particular. Kaye and Davitt [1995] have also commented that the number of organizations providing home care is growing at a "feverish pace". As of March 1994, the National Home Care Association [1994, cited in Kaye, 1995, p. 1] identified a total of 15,027 home care agencies in the United States. Home care is one of the fastest growing components of the health care delivery system, with a growth rate of 15 to 20% per year. Estimates of total home care spending (from sources including Medicare, Medicaid, private insurance and out-of-pocket payments) varied from US$23.7 to US$29.9 billion in 1994, roughly 3% of national health care spending.

Kaye [1995, p. 3] expresses concerns about this hastened development: "the fact that home care exists in so many shapes and forms leads to questions about the capacity of such providers to deliver home care services in a consistent manner reflecting high levels of effectiveness and efficiency." This kind of concern should, in fact, remain at the root of home care development. Home equipment should be designed in order to fill existing gaps in our ability to respond to health needs. Thier [1988] suggests that physicians should develop a framework for technological innovation, ranking prevention and screening higher than therapeutic interventions. The common objective of medicine, engineering, and industry should be to select the most appropriate use of new technologies in support of health gain, not to protect physicians from liability nor to enable a manufacturer to develop a new device. Because the setting in which these technologies will be used differs from the hospital, questions specific to their user-friendliness should be examined from the viewpoints of both the professional providers and the lay persons. Finally, we should also be aware of social innovations (e.g. self-help groups, respite care) that may improve home care services [Baldock, 1991].

5.3.4 Recommendation 4: Support high-quality research into the cost-effectiveness of home care

Despite a vast literature on home care, data about the effectiveness of different home care delivery models are limited. The lack of reliable information systems may partly explain the paucity of published data. Another explanation lies in a 'piecemeal' health technology assessment approach, which focuses on the effectiveness of one specific technology but pays little attention to the organizational context in which it is used. The synthesis report of the National Evaluation of the Cost-Effectiveness of Home Care program insisted that "the policy discourse should now shift from home care to the broader system of continuing care (long term care, home care, and case management)" [Hollander and Chappell, 2002]. This report has indeed emphasized how important it is to understand, in the case of home care, the role of the broader environment on the effectiveness of technology. More research should be conducted on home care services, especially cost-effectiveness studies of the use of technology. Efforts should be devoted to both the production of new evidence and the synthesis of existing evidence. However, supporting the production of research is far from enough. The results of such studies should be widely disseminated and discussed with key decision-makers and clinicians. As already indicated, home care is not a static, homogeneous category of interventions. Its impact on social and health system costs depends on the health condition and on the way services are provided and organized [Soderstrom et al., 1999]. For instance, substitution for hospital care (e.g. timely discharge, reduced hospitalization rate) is key to ensuring the financial benefit of certain home care programs. Given outstanding challenges in the methodology and controversy in the interpretation of the results of cost-effectiveness studies, it seems important to create specific forums in which the cost-effectiveness of home care programs could be clarified and debated amongst practitioners, researchers, and policy-makers. Clinicians, hospital-based home care program managers, CLSC home care program managers, researchers, and planners from the MSSS should attend such forums as some form of consensus might be reached with respect to what type of home care interventions should be supported in Québec. Several notions need to be clarified and understood, notably: How is home care effectiveness measured? What kinds of costs should be measured and from what perspectives? What happens when home care is more costly than hospital care but as effective? How can coordination mechanisms be used to guarantee cost-effectiveness?

6 CONCLUSION

Home care is an area that calls for immediate policy action. Sophisticated technology is changing the nature of health systems across industrialized countries, and one of its most significant facets is the use of complex equipment in the patient's home. The use of such equipment often requires the expertise of secondary and tertiary care level clinicians as well as a keen understanding of home care patients' needs, an expertise that CLSC home care program staff have developed over the last two decades in Québec. One critical challenge, for the next decade, will be to combine these two types of expertise in order to provide technology-enhanced home care that remains meaningful for patients and their relatives, while being effective from a clinical and organizational perspective. In this endeavour, coordination among care providers and among health organizations is central, as well as building the technical and clinical competence of providers, patients, and caregivers. All of these issues were central in the Romanow Commission [2002, p. 171], when referring to home care as the "next essential service."

While the federal government has launched important initiatives to foster both research and information technology projects in home care, the provinces have a direct responsibility to ensure that the provision of home care services remains of high quality, evidence-based, and responsive to patients' and caregivers' needs. This report summarizes issues in organization and delivery that should be addressed by home care providers and decision-makers in Québec. Four primary recommendations have been laid out, each of which addresses a facet of the 'technology-enhanced home care problem'. While a global, provincial vision of technology at home should structure the future of home care in Québec, regional leadership is required to support and implement organizational incentives that will enable effective coordination between hospitals and CLSCs. Regional health authorities should be in a good position to identify the priority health needs of their community, while being aware of the opportunities and constraints affecting the use of technology in their area.

6.1 WHOSE DECISIONS AND ACTIONS SHOULD BE INFLUENCED BY THIS REPORT AND HOW?

As per Battista et al. [1999], there are three decision-making levels that have an impact on technology use (Box 6). This report is intended to help all of these actors better understand each other's contributions and responsibilities in the multifaceted world of home care.

BOX 6

Whose decisions and actions should be influenced by this report?

Macro level: refers to the aims and means of policies formulated by the provincial government and by regulatory bodies with a provincial mandate (e.g. RAMQ).

- By using the information provided within this report, the *Ministère de la Santé et des Services sociaux* (MSSS) and the *Ministère du Développement économique et régional* (MDER) could inform their policy on technology in home care.
- The MSSS could adjust its existing home care programs in order to alleviate the possible negative impacts, maximize the benefits, and take into account the social implications underlined by this report.
- The MERD could develop diverse incentives (e.g. targeted funding and knowledge transfer programs, R&D-related tax deductions) that will push the home medical equipment industry to develop safe and effective devices that respond to the health needs of the Québec population.

Meso level: refers to the organizational and institutional mechanisms available for managing home care programs (accreditation, budget allocation rules, etc.).

- This report can inform Regional Health Authorities, the *Association des CLSC et CHSLD du Québec*, the *Association des hôpitaux du Québec*, the directors of home care services in hospitals, the coordinators of home care programs in CLSCs, and the directors of biomedical engineering services in hospitals.
- Regional Health Authorities could include some of the organizational principles highlighted in this report in their budget allocation process. They could also investigate further the problems that local CLSCs are facing in the development of home care programs that rely on new technology.
- Both the *Association des CLSC et CHSLD du Québec* and the *Association des hôpitaux du Québec* (*AHQ*) could extend the information provided in this report to develop organizational measures that would help CLSCs and hospital ambulatory services to coordinate their interventions.
- The contribution of biomedical engineers is crucial in ensuring that the equipment used complies with safety standards, that appropriate maintenance protocols are developed and implemented, and that technical hazards are reported swiftly.

Micro level: refers to the principles governing medical practice and the patient-provider relationship (e.g., clinical guidelines and professional codes of ethics produced by the *Collège des médecins du Québec* (CMQ) or *Ordre des infirmières et infirmiers du Québec* (OIIQ), the consumers' association lobby, etc.).

- With this report, physicians initiating the home care episode may better appreciate how the clinical criteria they set for admission/discharge may have social and ethical implications in patients' lives.
- As nurses are the ones largely responsible for providing both patient education and home care services, they could advocate for greater consideration of specialized training for professionals and methods of training patients.
- The organizations representing care providers' responsibilities (OIIQ, CMQ) could contribute to enhancing home care delivery by translating the clinical and organizational observations found in this report into clinical guidelines.
- With the collaboration of organizations responsible for defending care providers' rights (*Fédération des infirmières et infirmiers du Québec* [FIIQ], *Fédération des médecins spécialistes du Québec* [FMSQ], *Fédération des médecins omnipraticiens du Québec* [FMOQ]), educational programs could also be developed to reinforce the use of guidelines and stimulate research targeted to the providers' needs in the area of home care.
- Finally, it is hoped that patients as well as caregivers associations in Québec will be involved in the discussions that will shape the future of home care.

APPENDIX: REFERENCES GROUPED BY TOPICS

More than 200 documents were consulted during the preparation of this report. A full list of the references alphabetically sorted appears at the end of the report.

The tables below were created in order to help the reader locate useful papers related to a specific topic. The following nine categories were used:

Table A-11 Governmental publications (Canada, Province of Québec, USA) 63
Table A-12 Health organizations publications 65
Table A-13 HTA agencies and research groups publications 66
Table A-14 Clinical dimensions (nursing care, effectiveness, safety, etc.) 67
Table A-15 Organizational dimensions (including patient education) 69
Table A-16 Social dimensions, with special emphasis on user's perspective 74
Table A-17 Ethical and/or legal dimensions 76
Table A-18 Medical equipment and R&D issues 78
Table A-19 Other (costs, methodological aspects) 80

TABLE A-11

Governmental publications (Canada, Province of Québec, USA)

N°	1ST AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
1.	Boudreau (*Ministère de la Santé et des Services sociaux* [MSSS])	1997a-j	Consultation document	Québec health system	The integrity (access, equity, quality, publicness) of the Québec health system should be preserved. Nonetheless, efforts to modernize the system, adapt it to population health needs, and keep it competitive towards other industrialized countries systems should be pursued.
2.	*Conseil de la science et de la technologie* (CST)	1993	Policy document	Study on medical technology industry in Montreal	As in the rest of Canada, the medical technology industry in Montreal is weak. Regulation of medical device and public nature of the health system are significant barriers. Low levels of R&D are observed despite the potential of development university-based expertise represents.
3.	Dumont-Lemasson	1999	Report prepared for Health Canada	Provincial and Territorial home care programs	There is considerable variation among home care programs across Canada. All programs are in a period of growth and new development. The development of systematic information and data collection should assist policymaking.
4.	Health Canada	2000	Canada Health Act Annual report	Information provided by provinces/territories on Canada Health Act	Information about the compliance to the five national criteria (publicness, comprehensiveness, universality, portability, and accessibility) is reported for each Province/Territory.
5.	Health Canada	1999	Report	Identification of priorities for home care development	Report on the National roundtable on home and community care. Identification of priorities for future action and potential strategies and partnerships for home care development.
6.	Health Canada, P&CB	1998a	Fact sheets	Public home care expenditures in Canada (1975-76 to 1997-98)	Public home care expenditures have more than doubled in the last seven years, an average annual rate of increase of almost 11%. Public home care spending accounts for a small but increasing percentage of total public health spending.
7.	Health Canada, TDP	1998b	News Bulletin	Changes in regulation of medical devices	This issue of the newsletter provides information about the latest changes in the Canadian regulation and future orientations.
8.	Health Canada, Office of Health and the Information Highway (OHIH)	1998c	Background paper for discussion	Home telecare	Canadian home telecare is in its infancy. Despite the lack of funding, industry champions are emerging. There may be a potential to develop knowledge centres that could contribute to the dissemination of the technology.
9.	Hébert (MSSS)	1997	Report prepared for MSSS	Clinical assessment and costs analysis of services to elderly patients	Caregivers should be supported financially. CLSCs services should be better organized (time spent travelling and doing administrative tasks). Benefits of the privatization of nursing homes are not evident. Assessment of the patient autonomy is pivotal.
10.	Locas (MSSS-*Direction de l'intégration locale*)	1995	Policy document	Home care delivered by CLSCs (1988-93)	Comparative analysis of annual surveys on home care delivered by CLSCs (1988-93).
11.	MSSS	1999	Guidelines	Information system on the clients of CLSCs	This document defines the type of information that CLSC should compile regarding the clients, services required and provided, status and type of providers involved, and follow-up.

TABLE A-11

Governmental publications (Canada, Province of Québec, USA) (cont'd)

N°	1ST AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
12.	MSSS	1996	Statistics	Public expenditures for social services	Public expenditures for social services in Québec (1986-96).
13.	MSSS Expert group in clinical organization	1998	Policy report	Hospital-based ambulatory care centres	Several clinical and economic benefits are associated with ambulatory care. However, a critical mass of specialized expertise, patients, providers and technologies is required. Dispersion of services is likely to increase patient mobility and reduce the overall effectiveness of services.
14.	MSSS & Québec Ass. of Nephrologists	1995a	Policy document	Funding and management of dialysis services in Québec	Dialysis services are expensive for both the patient and the State. Hospital-based dialysis centres represent a significant portion of hospital costs. Original solutions should be sought to offer quality services to an increasing patient population.
15.	MSSS & Québec Ass. of Nephrologists	1995b	Results of a survey	Survey on patients receiving dialysis services in Québec	The dialysis patient population is changing rapidly and the geographical distribution of services is uneven. Stakeholders should work together to enhance the organization of services in Québec.
16.	MSSS & Québec Ass. of Nephrologists	1995c	Policy document	Organization of dialysis services in Québec	The organization of dialysis services in Québec is facing significant challenges: high costs, increased number of patients, and geographical distribution of centres. The proportion of patients with autonomous treatment should be increased to 50%, support services to patients should be increased, and Regional Health Authorities should define how these objectives will be reached.
17.	Namiash Health Canada	1992	Report prepared for Health and Welfare Canada	Private home care services in Canada	Based on case studies, survey and interviews, this report describes three areas of concern: the need for improved quality controls and standards; the need for formal evaluations of existing and new programs; and the need for outcome research addressing equality of access, cost-effectiveness and client expectations.
18.	Trahan (MSSS)	1998	Policy document	Self-sufficiency of regions in terms of ambulatory and hospital-based medical services	Detailed data is provided for each Québec region and for divers services, and objectives of retention of clients are given in relation to existing levels of retention.

TABLE A-12

Health organizations publications

N°	1ST AUTHOR	YEAR	DOCUMENT	FOCUS	CONCLUSIONS
1.	*Association des CLSC et CHSLD du Québec*	1998a	Report	Guidelines of access to medical and assistive devices	Québec CLSCs are invited to adopt the suggested guidelines on access to medical and assistive devices.
2.	*Association des CLSC et CHSLD du Québec*	1998b	Report	Changes in home support	Five home support client profiles are defined according to their level of dependence and safety needs. The implementation of the self-managed home support program needs to be examined. Organizational and clinical interfaces with the social economy organizations should be secured.
3.	Association des CLSC et CHSLD du Québec	1998c	Position paper	Québec reform	Local organizations are pivotal for the success of the reform. The private sector should develop within the public system. A better collaboration between primary and secondary care providers is required.
4.	*Association des hôpitaux du Québec* (AHQ)	1997	Report	Hospital-based ambulatory care delivery models	Hospitals are increasingly providing ambulatory care services, which are often less costly and less invasive. Each hospital should implement a model of care organization that remains flexible, as technology is changing rapidly. Communication and coordination between health organizations is crucial.
5.	Becker	1997	Proceedings	Trends of the 21st century	Proceedings of the Insight Conference on home health care.
6.	Canadian Home Care Association (CHCA)	1998	Report	Portrait of home care programs across Canada	Report prepared for the National Conference on Home Care held in March 1998 in Halifax, NS. Each province/territory home care program is described individually.
7.	*Collège des médecins du Québec* (CMQ)	1996	Report	Perceptions of public on the Québec reform	Report from a population survey.
8.	Dunning But will it work, Doctor?	1997	Report	Making information about the outcomes and effectiveness of services accessible to consumers	Report of a 2nd conference held in UK. Constraints and barriers to the dissemination of information to users of health services should be removed. Patient information should be evidence-based. Research should address questions relevant for patients.
9.	Dunning But will it work, Doctor?	1994	Report	Making information about the outcomes and effectiveness of services accessible to consumers	Report of a conference held at the King's Fund Centre, UK. Users of services should know as much as possible. Trust and partnerships between providers and patients should be promoted.
10.	Larsen	1996	Proceedings	Trends in home care	Proceedings of the Insight Conference on community care. An overview of home care programs across Canada is given. This time of change offers opportunities. One should be creative, help his/her partners solve problems and work in collaboration.
11.	Sharkey	1996	Proceedings	Trends in community care	Proceedings of the Insight Conference on community care.
12.	The Caregiver	1999	News bulletin	Caregiver fears	News bulletin published by the Caregiver Network. This issue defines the most common fears experienced by caregivers.
13.	The Wilkerson Group	1995	Report	Opportunities and threats in the medical device industry	Report prepared for the US Health Industry Manufacturers Association.
14.	Wilson	1996	Report	Relationships between self-help groups and professionals	Report prepared for the British Association of Social Workers. If the autonomy of the self-help groups and the professionals groups can be protected, the potential of self-help groups can be developed to the mutual benefit of both worlds.
15.	Women's Association for Social Education and Action	1998	Report	Impact of the Québec reform and of social economy on women	Report prepared by Women's Association for Social Education and Action for Women Conditions Canada.

TABLE A-13

HTA agencies and research groups publications

N°	1ST AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
1.	CETS (*Conseil d'évaluation des technologies de la santé du Québec*) (now AETMIS)	1996	HTA report	Assessment priorities in ambulatory services	The *Conseil* consulted key experts in order to identify five priority topics for assessment: reduced length of stays in perinatal care; laparoscopic cholecystectomy as one-day surgery; ambulatory care centres in cardiology; economic model of alternatives to hospitalization; and comparative analysis of one-day organizational models in medicine.
2.	CETS	1990	HTA report	Home oxygen therapy	Provincial guidelines defining the therapeutic indications (severe hypoxemia measured twice over a 3-week interval or average hypoxemia associated with pulmonary heart disease) of oxygen are required. Portable oxygen increases patient compliance to treatment, quality of life and length of survival.
3.	Champagne *Groupe de recherche interdisciplinaire en santé* (GRIS)	1997	Research report	Advantages and disadvantages of different ambulatory care centres	There is no one best way to organize a hospital-based ambulatory care centre. Each hospital should pay attention to coordination mechanisms, staff training, patient involvement, and costs of implementation.
4.	Devins	1995	Research report	Psychosocial impact of end-stage renal disease	Although their quality of life may be threatened at times, the majority of people in treatment are able to establish a positive psychosocial adaptation. Early identification and psychoeducational preparation produce valuable results.
5.	HSURC (Health Services Utilization and Research Commission)	2000	HTA report	Impact of preventive home care and seniors housing on health outcomes	Retrospective analysis of administrative records indicates that seniors receiving preventive home care were 50% more likely to lose their independence or die than those not receiving any service. The average total costs for preventive home care recipients were triple the average total costs for non-recipients. Residents of seniors housing were 63% less likely to lose their independence and 40% less likely to die. Residents had about the same total costs as non-residents. Seniors housing appears more effective and less costly than preventive home care.
6.	HSURC	1996a	HTA report	Measuring the effectiveness of home care	Recommendations are made concerning the measurement of life satisfaction, health-related quality of life, patient satisfaction and caregiver burden. Key findings from the literature on such measurements are summarized.
7.	HSURC	1996b	HTA report	Cost-effectiveness of home care	The quality of existing research is limited. Little research has been done in the Canadian setting. Cost-effectiveness of home care must be considered on a case-by-case basis for each type of intervention.
8.	Martel	1992	Research report	Assessment of the home-based IV therapy program	Home IV therapy is safe and effective. The program helped the patient acquire autonomy, skills and enhanced quality of life. Organizational factors are crucial.

TABLE A-14

Clinical dimensions (nursing care, effectiveness, safety, etc.)

N°	1ST AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
1.	Branger	1995	Research journal article	Laboratory services utilization in ambulatory care	There is a need for better coordination of care between doctors treating the same patient, as repeat investigations could be reduced.
2.	Brooks	1998	Professional journal article	Electronic tracking	Electronic tracking to record staff exact arrival and departure time of visits using good old phone lines offers several benefits to home care agencies, including savings.
3.	Brown	1996	Professional journal article	Innovations in home care	A new breed of advanced practice nurses is required to provide cost-effective, quality care. Nurses with skills in case management, outcomes management, research and education, and program development are needed.
4.	Catanzaro	1998	Professional journal article	Wound and ostomy care in the home setting	Critical care nurses will require a broader base of expertise as wound, ostomy and fistula management services are provided at home.
5.	Chan	1998	Professional journal article	Approaches in pediatric home care	Complex, high-tech pediatric home care should be of high quality, demonstrated through cost-effective analysis, clinical outcomes, and patient and family satisfaction summaries.
6.	Creel	1996	Professional journal article	Trends in home cancer care	Providers interested in starting home chemotherapy should review a Joint Accreditation Manual section and the Oncology Nursing Society guidelines. Effective education programs for nurses are required.
7.	Dougherty	1998	Research journal article	Pediatric home care	An important decline has occurred in the absolute and relative rates of pediatric hospitalization. The need for specific services should drive the need for hospitalization, not the diagnosis.
8.	Erickson	1996	Professional journal article	Clinical pearls in home health care	Analysis of Ms. Wiedmer's oral history has elicited innovations (therapeutic activity board, bed shoe, adapted bath sponge, etc.) that can benefit home care patients.
9.	Goode	1993	Editorial	Drug monitoring in ambulatory care	A pharmacist-managed therapeutic drug monitoring service should improve patient care, contain costs, and enhance education of pharmacy/medical students.
10.	Grin	1993	Research journal article	Ambulatory blood pressure monitoring	Cross-sectional assessment of physicians' habits and a longitudinal study of patient management indicated that physicians use ambulatory blood pressure recordings for appropriate indications. Data from the monitoring studies affected the management of patients with hypertension. Further research is needed to identify changes in outcomes and cost-effectiveness.
11.	Helberg	1993	Research journal article	Factors influencing home care nursing problems	Based on patient interviews, direct observation and records, this study indicates nursing dependency (physical and instrumental activities of daily living, family coping index) is the strongest predictor of the nursing problems.
12.	Howell	1998	Professional journal article	Nursing supportive care through the internet for cancer patients	Access to a supportive care program is crucial for cancer patients and their families. Oncology nurses can make a significant impact on the outcomes of cancer.

TABLE A-14

Clinical dimensions (nursing care, effectiveness, safety, etc.) (cont'd)

N°	1st AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
13.	Kafka	1998	Professional journal article	Home care and the disabled community	The home care and the disabled community should be turning to care based on a social model of service delivery instead of a medical model.
14.	Kaye	1995a	Book chapter	High-tech home care	Technology will be more widely available to the functionally impaired, community-based elderly population. Home health care providers should encourage elders to assume greater involvement in their own health maintenance as home environments are designed to maximize an individual's functional independence.
15.	Kraus	1994	Professional journal article	Transition to high-tech home care	Nurses newly employed in high-tech home care facilities face seven transitional stressors: differences in health care settings, adaptation to a corporate environment, decrease in peer support and contact, responsibility for new treatments, increased independence and isolation, problem solving without direct patient contact, and personal and professional self-esteem issues.
16.	Lindeman	1992	Professional journal article	Nursing and technology	Nurses need to supplement their knowledge base in nursing interventions with extensive knowledge in ethics, health care financing and technology. One goal of nursing education is to prepare practitioners who can combine safe high-tech with meaningful high touch.
17.	McNeal	1998	Professional journal article	Information technology in home care	Client self-management of complex interventional therapies will require the support of nurses. Information technologies that will affect nursing practice are described.
18.	Monk	1995	Book chapter	International perspective on home care developments	The connection between the formal service system and the families and relatives of the home care patient remains unresolved. Only Denmark has progressed on that point by recognising that the number of older persons living alone is increasing while their networks of children and relatives are shrinking.
19.	Newell	1998	Professional journal article	Transitions in home care	Besides maturity and autonomy, home care nurses need to know more about insurance systems, diagnosis coding and outcomes tools. The whole continuum of care needs to be taken into account.
20.	Petit de Mange	1998	Professional journal article	Pediatric considerations in high-tech home care	Parents assume caregiver roles that professionals have taken years to develop. High-tech home care is comprised of multiple dimensions. Nurses are challenged by cultural differences, language barriers, loss of control, family dynamics, unfamiliar environments and new technology.
21.	Petty	1996	Professional journal article	Oxygen systems and mechanical ventilator at home	The challenges for the late 1990s include the world wide application of oxygen. Russia, China, Africa and Central Asia have low access to oxygen. Advantages are not only economic but social and spiritual.
22.	Rosenfeld	1998	Research journal article	Home nebuliser use among patients with cystic fibrosis	Disposable nebulisers are often used by patients for long periods. Mixing of medication is common, although its effects on aerosol properties are unknown. Cystic fibrosis pathogens are frequently isolated from nebulisers. Patient guidelines are needed.
23.	Suther	1999	Professional journal article	High-tech home care at the VNA in Texas	High-tech services offered by the VNA of Texas are described.
24.	Zarbock	1996	Professional journal article	Home care in rural areas	In rural areas, home care raises specific issues. Patients should become more involved in home care and professionals should experience a greater sense of mutual cooperation.
25.	Zerwekh	1995	Professional journal article	High-tech home care	Nurses are the advocates for the people whose lives the technology must serve. They need to encourage patients and families to speak the truths about their lives and make conscious choices about the worth of technology.

TABLE A-15

Organizational dimensions (including patient education)

N°	1ST AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
1.	Allen	1995	Commentary in professional journal	Delivery considerations in parenteral pharmaceutical care	As home health care in general and the use of biotechnology drugs in particular will flourish and require specific handling, storage and administration methods, the role of pharmacists will increase.
2.	Baldock	1995	Book chapter	Policies of care for the elderly in three European countries (conclusion)	There are social innovations that may improve home care services. Home care potentially expands individual choice but only if public policy shifts extend definitions of social rights. The rights and welfare of carers should be taken into account.
3.	Baldock and Evers	1995	Book chapter	Policies of care for the elderly in three European countries	Five imperatives are noticeable among home care policies: innovation, targeting, case management, balance of care, and mixed-economy-of-care imperatives.
4.	Benjamin	2000	Research journal article	Consumer-directed agency models	Based on a telephone survey of home care patients, this study indicates that recipients in the consumer-directed model report more positive outcomes than those in the agency model. Significant differences emerge on recipient safety, unmet needs and service satisfaction. Model differences persist when a family member is present as a paid caregiver.
5.	Benson	1996	Professional journal article	Information technology in home care agencies	The need to measure benefits in client care and outcomes associated with information technology has never been greater.
6.	Boling	1992	Research journal article	Referrals to home health agency by internists and family physicians	According to a telephone survey with physicians, internists and family physicians who work at least 10 hours per week in ambulatory care report three referrals per month and spending substantial amount of time coordinating home care. Rural physicians report greater involvement than non-rural physicians.
7.	Burman	1992	Research journal article	Organizational dimensions of VNAs home health care	Based on a national US mail survey, the paper indicates that recent changes in the home care scene have led to a blurring of the distinctions between the Visiting Nurses Associations (VNAs) and Hospital-Based Home Healthcare Agencies (HBHHAs). Some organizational differences (funding sources, referral sources, accrediting bodies) are linked to their differing origins: VNAs as public health independent community-oriented agencies; HBHHAs as hospital-connected continuity-of-care-oriented agencies.
8.	Carruth	1999	Research journal article	Perceptions of caring behaviour related to primary and modular nursing delivery systems	Based on interviews with cancer patients and their caregivers, this study indicates that the longer a patient stays in the hospital, the greater the likelihood the patient and family members will feel nurses exceeded expectations for caring. No differences were found in caring scores between primary care and modular care.
9.	Coleman	1995	Research journal article	European models of home long-term care	European countries have emphasized informal care; decentralization of funding; inclusion of the private sector; provision of services tailored to specific needs of clients.
10.	Calvez	1996	Research journal article	Subjective and objective determinants of home aid allocation for elderly patients	A survey of patients indicated that factors positively associated to allocation of home aide were: age, disabilities in instrumental activities of daily living and mobility. Factors negatively associated were: level of income and disabilities in physical activities of daily living. Subjective factors influence home aid allocation.

TABLE A-15

Organizational dimensions (including patient education) (cont'd)

Nº	1ST AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
11.	Coyte	1999	Research journal article	Regional variations in the use of home care services in Ontario	Data from the Canadian Institute for Health Information and the Ontario Home Care Administration System database were used to assess variations in the rates of home care use following inpatient care and same-day surgery. There was a 3.5-fold regional variation in the rates of home care use following inpatient care and 7-fold variation following same-day surgery. It is important to modify home care funding to ensure all residents of Ontario have equal access to services. A substantial increase in funding is warranted.
12.	Dansky	1996	Research journal article	Hospital referrals to home care agencies	Hospitals are actively using referral to home care in response to environmental pressures (urban vs. rural). Hospitals would benefit from tight linkages with home care providers.
13.	Davitt	1995	Research journal article	Administrative and staff perspectives on high-tech home care	This study examines staff perspectives and personnel issues to delivery of high-tech home care services. Data were collected from a national sample of 154 agency directors and 92 agency staff. Most staff feel high-tech care enhances the quality of life of older patients, although it is difficult to deliver.
14.	Doherty	1998	Research journal article	Interdisciplinary critical care team at home	The development of sophisticated interdisciplinary models of practice in high-tech home care supports the provision of holistic care by nurses.
15.	Evers	1991	Book chapter	Policies of care for the elderly in three European countries (introduction)	A framework for analyzing patterns of change in welfare systems is presented (flexibility vs. standardization, bureaucratic centralism vs. regulated pluralism, implicit vs. explicit interaction with informal care systems, separate vs. integrated economic criteria).
16.	Forrest	1996	Research journal article	The impact of first-contact care on ambulatory care expenditures	According to a cohort study, the use of an identified primary care source for the first visit in an episode (first-contact care) was associated with reductions in ambulatory episode-of-care expenditures of over 50%.
17.	Forster	1992	Professional journal article	Status of the independent home care provider	Independent provider programs may not include the high costs of employee education and oversight. However, tragic consequences may result from inadequate training, difficult to quantify in terms of costs.
18.	Gabel	1993	Research journal article	Factors explaining why patients see the same physician over time	Based on interviews with patients, this study indicates that the factors associated to a continuous care relationship were: patient familiarity with the physician, physician knowledge of the patient, patient satisfaction with care received, and patient confidence in the physician. Personal attributes of the physician, friendship with physician, ease of communication and professional growth of the physician were also related. The availability of the physician and the location of practice were reasons to start consulting a physician.
19.	Gorski	1995	Professional journal article	Patient education in high-tech home care	Patients and caregivers must clearly understand and comply with home care regimen. Nurses' knowledge and skills in patient education are as important as her/his skills in technical procedures.
20.	Handy	1995	Book chapter	Alternative organizational models in home care	Traditional models of home care are likely to be altered by integrated service delivery systems, in which home care has a closer alignment with other levels of care in a continuum.
21.	Hartley	1987	Research journal article	Physicians' use of medical resources in ambulatory settings	Analysis of ambulatory patient forms indicated that physicians who saw more frequently their patients referred and prescribed for them more often and ordered more tests. Greater frequency of patient-physician contact increases costs through more professional time and greater use of other ambulatory resources.
22.	Huba	1998	Research journal article	Retention of clients under tow models of home care for HIV/AIDS	A RCT showed that an integrated model of service delivery, based on interdisciplinary care-management and blended modalities of service, provides a quality of life enhancement and a cost-effective method in provision of home care for terminally ill AIDS patients.

Organizational dimensions (including patient education) (cont'd)

N°	1ST AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
23.	Johansson	1991	Book chapter	Policies of care for the elderly in three European countries	Meeting the needs in housing, service and care for the elderly is a tremendous challenge to the Swedish welfare society. The existing care system should be developed through modernization and rationalization.
24.	Kane	1995	Book chapter	Organizational and ethical dimensions of high-tech home care	The fragmented financing and delivery systems of home care in USA lend themselves poorly to providing both high-tech and low-tech home services. Fragmentation between home care sectors interferes with continuity of care and diminishes accountability for quality.
25.	Kangas	1999	Research journal article	Organizational factors, nurses' and patients' satisfaction	A survey revealed that nurses' job satisfaction did not vary according to the care delivery model. Organizational culture was more important than the type of unit and specialization. Differences in patient satisfaction with nursing care remained unexplained.
26.	Kaye	1998	Research journal article	Comparison of high-tech service delivery experiences by hospice vs. non-hospice providers	Hospice agencies employ more part-time staff, make more in-home visits, see more high-tech patients, and provide a wider range of high-tech services than non-hospice providers. Hospice staff has more experience addressing legal and ethical dimensions (right to die with dignity, patient rights, delegation of authority). However, policies for dealing with limited patient decision-making capacity are needed.
27.	Kaye	1995	Research journal article	Differential access to high-tech home care	This study examine the type of services offered by US home health care agencies (n=154). Proprietary programs have grown faster. One patients in 10 receives high-tech home care. These patients are more likely to be younger, white, married men, living with others.
28.	Kendix	1995	Research journal article	Provision of home dialysis by freestanding facilities	Analysis of three databases on renal dialysis patients revealed that a negative association was found between the number of facilities per square mile and the probability of provision of home modalities. Facilities with a higher percent of black patients were less likely to provide home modalities. Facilities with larger numbers of patients were more likely to provide home modalities.
29.	Krause	1995	Professional journal article	Delegation in the home care delivery system	The introduction of high-tech home care encourages high-level professionals to provide care, while information technology fosters delegation. Some technological advances encourage delegation to the patients themselves. Standards for ongoing supervision and periodic verification of competence must be established and all related aspects documented.

TABLE A-15

Organizational dimensions (including patient education) (cont'd)

N°	1st AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
30.	Laberge	2000	Research journal article	Home visits by family physicians in the Quebec City region	A self-administered questionnaire was sent to 696 general practitioners in private practice, family medicine units, CLSCs or hospitals. Response rate was 70%. 58.1% of physicians surveyed made housecalls to a clientele consisting mainly of elderly patients (87.6%); 42% saw fewer than five patients per week and 31% spent 2 hours or less per week on housecalls. Only 22% of their patients were also receiving home care services from the CLSC. Difficulties with scheduling and reimbursement were perceived as barriers.
31.	Lyon	1993	Professional journal article	Models of nursing care delivery and case management	The objectives of nursing care delivery systems are to assess the patient, identify the nursing needs during hospitalization and provide the nursing care until the patient is discharged. The purpose of client-centered case management is to assist the client through a complex, fragmented and confusing health care system, while system-centered case management serves rationing and priority-setting functions as well.
32.	McNeal	1998	Professional journal article	Diversity issues in the home setting	The culturologically competent nurse should be able to obtain value-free cultural information and use this information sensitively in the development of plans of care.
33.	Meurer	1997	Professional journal article	New models of home and work site health care	Physicians should consider alternative models of care. Family physicians may contribute and coordinate care in the home and in the work site.
34.	Miller	1995	Professional journal article	Public reporting of performance measures in home care	The lack of accepted definition of home care outcomes measures is a significant problem. Collaboration with insurance companies in the data collection process is essential.
35.	Norman	1995	Professional journal article	Computer-assisted quality improvement in ambulatory care settings	Ambulatory clinics will need successful methods for providing continuity of care. Quality improvement computer-assisted tools are promising.
36.	O'Malley	1996	Research journal article	Continuity of care in ambulatory services to children	Based on a survey of children whose routine source of care was a community health clinic, this paper indicates that continuity of care was associated with a two-fold increase in the odds of receiving age-appropriate preventive care. Both routine and sick care services should be delivered in a single site.
37.	O'Sullivan	1997	Research journal article	Factors associated with achievement of goals for home care	A retrospective analysis of discharges for congestive heart failure and total hip replacement recorded in six home health agencies (New Hampshire), indicated that variability in likelihood of meeting goals for care is much better predicted by patient characteristics (diagnosis, age, functional limitations, prognosis, rehabilitation potential, presence of an able and willing caregiver) than by utilization of home care services.
38.	Pilling	1996a	Research journal article	Survey on purchasers' contracting for high-tech home care	Based on a questionnaire, this study indicates that after implementation of a UK governmental purchase policy (EL[93]5) purchasers emphasized continuity of care and contracted high-tech home care services initially from existing suppliers and later from the NHS hospital. Purchasers recognize the need to expand their own skills in setting and monitoring contracts.
39.	Pilling	1996b	Research journal article	Effective contracting for high-tech home care	Purchasers will need to consider a range of innovative contracting models. Clinical effectiveness and cost-effectiveness should guide the choice between competing alternatives.
40.	Richards	2000	Literature review	Skill mix between nurses and doctors in primary care	More equitable and less hierarchical models of multi-professional team working in primary care will have a greater chance of meeting the users' needs. Shared decision making and mutual respect should be core values, while ownership of care rests with the whole team rather than being confined to the medical profession.

Organizational dimensions (including patient education) (cont'd)

N°	1ST AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
41.	Rodriguez	1999	Research journal article	The role of community organizations (CO) in the Québec reform	A major transformation of the Montreal Regional Health and Social Services Board began in 1995. This paper presents the results of a qualitative study aimed at understanding the "*virage ambulatoire*" from the perspective of COs. Participants believe in the need for change but feel the implementation has been mismanaged. COs are striving to professionalise and specialize their services, as the "social economy" is gaining momentum in the health sector.
42.	Salazar	1996	Research journal article	Depression management in outpatient office	Current practice suggests that primary care physicians can identify initially and treat depression in the ambulatory setting. Depressed patients can present a variety of somatic and cognitive symptoms. Primary care physicians miss the diagnosis of depression in two out of three cases. Patients are often undertreated, given antidepressant at subtherapeutic dosages, for short periods of time. Educating primary care physicians is essential.
43.	Sawyers	1993	Professional journal article	Role of the nurse practitioner vs. the nurse specialist	Increased administrative and clinical responsibilities necessitate a clinical expert, combining both the clinical nurse specialist's role and the nurse practitioner's role.
44.	Sloan	1993	Research journal article	Effects of physician-to-patient ratio on follow-up in long-term care	The review of 60 patient charts in three intermediate care facilities showed that physicians with more than 17 patients followed up sooner that those with fewer than six. A "house doctor" (the nursing home doctor) model is recommended for patients whose follow-up is poor.
45.	Stearns	1993	Professional journal article	The teaching and practice paradigm of ambulatory care	A paradigm for ambulatory medicine should combine elements of traditional medical care (etiology, history, physical examination, laboratory tests and therapy) and of the ambulatory setting (continuity, context, health education, economics and responsibility).
46.	Tunissen	1991	Book chapter	Policies of care for the elderly in three European countries	In the early 1990s, the introduction of market elements and the proposed reform in the insurance system caused upheavals. Premiums were higher, user fees increased and cash payments in advance more frequent. Low income groups were likely to suffer.
47.	Wadhwa	1999	Systematic review	Impact of new models of health care delivery on quality of care to vulnerable populations	A criticism of conventional clinic-based models of care is that they focus on urgent problems and do not provide comprehensive assessments, education, and psychosocial support to patients. This review of 24 studies found that patient and caregiver satisfaction was consistently higher with innovative models. Functional, clinical, or psychological improvements were not consistently demonstrated. Multidisciplinary outreach strategies were effective for mentally ill patients. Further research is needed about costs and health improvements to identify whether higher satisfaction justifies a widespread use of innovative models.

TABLE A-16

Social dimensions, with special emphasis on user's perspective

N°	1ST AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
1.	Allwood	1993	Research journal article	User-competence associated to an administrative system	The most important deficiencies of an administrative system implemented in a Sweden radiology clinic were associated to the contract between the delivering consultant and the health authority, delays in the delivery of the program and manual, and a lack of concern in the project for software usability aspects.
2.	Berge	1995	Research journal article	User-friendliness of anaesthetic machines	The complexity of a anaesthetic machine can be reduced by replacing several components included to prevent hypoxic mixtures with a simple safety system cutting down automatically the nitrous oxide supply.
3.	Brooker	1997	Research journal article	User feedback on services for elderly people	Caution should be shown when interpreting high levels of user satisfaction. Structured interviews elicit more reliable forms of feedback from elderly groups.
4.	Brown	1997	Research journal article	Home-made aids for disabled elderly people	Health professionals visiting elderly people at home should look for home-made aids with a view to promoting safety and identifying solutions that may help others.
5.	Dahlof	1998	Research journal article	User-friendliness of a nasal spray	Compared to a tablet, the nasal spray was perceived as a little user-friendly by patients, while much more user-friendly compared to a subcutaneous injection.
6.	Darbyshire	2000	Professional journal article	User-friendliness of computerized patient record system	A focus group revealed that nurses' experience in using computers has been frustrating. Areas for improvements are: passwords, terminal access, navigability, interfaces, help function, prompts and reminders, printouts, and speed.
7.	Fetterman	1997	Research journal article	Design of assistive devices by a disabled person	A person's own disability is a trigger for creating and developing assistive devices that are more appropriate and easy to repair. Poor solutions may be frustrating although successful ones are a reward of their own.
8.	Joule	1993	Editorial	User involvement in health care	Users' views cannot be substituted by those of purchasers or providers. Appropriate and acceptable services can only be developed by integrating users' views into decisions about health services.
9.	Kaunitz	1997	Research journal article	User-friendliness of contraceptives	Recent studies provide reassurance regarding the safety, convenience and effectiveness of intrauterine devices.
10.	Kelson	1996	Research journal article	User involvement in clinical audit	Consumer involvement lacks any clear methods. Progress is needed: development of norms of good practice; development of organizational structures allowing for the evaluation of initiatives; and dissemination of evaluations for refining models of good practice.
11.	Lun	1995	Research journal article	User interfaces	Despite clear improvements, usability issues remain over the use of computer-based information systems. Issues associated with pen and voice technology are discussed with respect to user-friendliness, acceptance, and user-competence.
12.	Lupton	1993	Research journal article	User-involvement in health policy	The development of consumer involvement, although generally well received by providers and managers, need to be supported by systematic initiatives (staff training, resources, reallocation of tasks).
13.	Miyaji	1993	Research journal article	Truth-telling among American doctors in the care of dying patients	Doctors control information as they handle institutional and legal constraints, their own emotional coping, and power relationships among patients, doctors and other caregivers. Even though the humanistic role of the doctor is suppressed in the dominant contractual ethic framework, it remains powerful in their narratives and it preserves their authority.

Social dimensions, with special emphasis on user's perspective (cont'd)

N°	1st AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
14.	Perneger	1996	Research journal article	Patient satisfaction with ambulatory care	An easy to use, reliable and valid satisfaction questionnaire is presented.
15.	Pippin	1997	Research journal article	User-friendliness of assistive devices for frail elderly	The design of devices for the elderly should be based upon a balanced view of the importance of function and appearance. Therapists should examine user acceptance and gradually increasing physical impairment.
16.	Rogers	1992	Research journal article	User-friendliness of medical lasers	Ergonomics and human factors designs have helped operators define and describe the user-friendliness of laser systems.
17.	Schachter	1995	Book chapter	Social and psychological issues of high-tech home care	The benefits of home care outweigh the liabilities, which can be minimized by addressing the family's needs (information, health education, support, counselling, increased coverage, development in terminal illness care programs).
18.	Thomas	1994	Professional journal article	User-friendliness of computers in medical practice	The potential for development of computerized systems in health care is tremendous. However, users require that computers do work for them (not the contrary) and that using computers remain easily under their control.
19.	Watzke	1997	Research journal article	Elderly persons' responses to an automated environmental control device (ECD)	The participants stated a preference for ECD to be connected to household items enhancing personal safety, and did not associate its use with the potential prevention of in-home accidents.
20.	Wiklund	1995	Professional journal article	User-friendliness of medical devices	Design judgement will always be crucial in the development of medical devices. Established design principles, such as those of the Association for the Advancement of Medical Instrumentation, are a good starting point. Designers need to meet users, understand their needs, working environments and stresses, and foresee what could go wrong.
21.	Yager	1995	Research journal article	User-friendly tool for visually impaired	Computers, high resolution monitors, printers and scanners may help people with low vision read written documents. Hardware, software and processes need to be powerful and simple enough for such a system to be practical and affordable.

TABLE A-17

Ethical and/or legal dimensions

N°	1ST AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
1.	Arras	1995	Book chapter	Ethical and social issues of high-tech home care	Abstract discussions of risks, costs and equity do not capture the human dimensions of home care. Narratives of patients and caregivers help researchers and policymakers understand the ambivalence some may experience and the meaning of home care for their own identities and relationships with relatives.
2.	Bowers	1999	Professional journal article	Documentation that reduces risks for home care agencies	A medical record should be an organised, clearly written synopsis of a patient's course of care from admission through discharge.
3.	Brent	1992	Professional journal article	Safe Medical Devices Act (US)	The implications of the SMDA for the home care nurse and agency are described.
4.	Campbell	1997	Professional journal article	Legal and clinical issues in intravenous therapy	As nurses take responsibility for care of the IV cannula and infusion equipment, they should be able to recognize potential and actual complications and initiate immediate and appropriate actions.
5.	Côté	1992	Professional journal article	Development of a medical and hospital liability database in Québec	The REMEDHOS database could constitute the cornerstone of a strategy aimed at controlling the expansion of medical and hospital liability. It provides precise knowledge on problematic situations and the opportunity to take actions that will reduce the risks of lawsuits and the occurrence of harmful events.
6.	Fiesta	1999	Professional journal article	Equipment related liability	Providers and manufacturers have a joint responsibility to ensure patient safety. Risk management review should include training and monitoring employees' use of new equipment, and compliance to the SMDA.
7.	Freed	1999	Research journal article	Mandatory reporting of abuse	Moral, legal, and practical decisions are those actions determined to be in the client's best interest taking into account the nurse's professional responsibility.
8.	Friedman	1997	Professional journal article	Risk management strategies for home transfusion therapy	Legal liability and risks can be significantly reduced when competent clinical staff applies accepted standards of care.
9.	Husted	1999	Professional journal article	Brochure on advanced directives for elderly people	Participants understood 90.5% of the content and found the brochure attractive.
10.	Joy	1998	Professional journal article	Doctors' responsibility in reporting death in the home	The role of physicians when patients die at home is ill-defined. The physician's duties are directed toward how our society deals with the bureaucratic and legal aspects of death. Providing valid information to the medical examiner is crucial.
11.	Kapp	1995a	Book chapter	Legal and ethical issues in home care	Legal and ethical implications of home care are dynamic. Home care agencies must redefine the patient's and family's responsibilities, the staff liability, and face legal and ethical challenges proactively.
12.	Kapp	1995b	Book chapter	Ethical and formal issues for dying at home	Dying at home requires the support of family and of physicians and other caregivers for general humanitarian and comfort care during what may be a slow and draining process.
13.	Kjervik	1998	Professional journal article	Legal considerations at the end of life Ad	Nurses can assist patients and their families to understand legal rights and responsibilities and encourage them to act upon this knowledge. vance directives, competency assessment, assisted suicide, and criminal and disability laws are discussed.

Ethical and/or legal dimensions (cont'd)

N°	1ST AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
14.	Koepke	1988	Research journal article	Legal issues in home blood transfusions (HBT)	Legal issues in HBT are reviewed according to corporate negligence and respondeat superior theories of liability. Standards of care are discussed.
15.	McCabe	1995	Book chapter	Ethical issues in long-term care for persons with HIV/AIDS	One needs to be creative in expanding the current programs in the community. High-tech home care is only one aspect of a comprehensive outpatient program for HIV/AIDS patients. Patient debilitation and social isolation are major challenges.
16.	Meade	1999	Research journal article	Improving understanding of informed consent	Conceptual and methodological limitations of research aimed at enhancing patient-provider interactions and information delivery systems are described.
17.	Nadash	1998	Professional journal article	Delegation and liability issues	An agency's decisions to permit delegation should be based on assessment of existing laws and regulations, the complexity of client needs and stability, and the training and clinical competence of the home care aide.
18.	Ruddick	1995	Book chapter	Transforming homes and hospitals	Stereotypes about home as a place of security, privacy and comfort distort our assessment of the transfer of equipment and care to a patient's home. Illness may transform deeply family life and home. In such cases, hospitals may allow patients greater autonomy than home and may better preserve family relationships.
19.	Scales	1996	Continuous Nursing Education	Legal and clinical issues in intravenous therapy	Professional nursing practice, underpinned by research and accurate documentation, should offer the patient and the nurse equal protection.
20.	van Raak	1996	Research journal article	Legislation related to home care policy reform in the Netherlands	Based on a retrospective analysis of policy documents, this paper indicates that several factors hindered the legislation and rules required for a successful implementation of the Dutch home care policy reform (1986-94). The implementation of a large-scale, far-reaching and integrated policy plan is more difficult than the implementation of separate policy measures.
21.	Verry	1997	Nursing case report	Safety in home care of elderly people	A patient case is discussed while highlighting the right to self-determination, safety of the patient, the agency staff and the patient's neighbours, the Medicare regulation, and the state law.

TABLE A-18

Medical equipment and R&D issues

Nº	1ST AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
1.	Altman	1988	Book chapter	Impact of payment system on technological innovation	DRGs should not always be applied (i.e., cardiac pacemakers, magnetic resonance imaging and penile prostheses). Blended reimbursement rate, based on a patient-specific amount and a national rate per diagnosis, should be used. PPS generates wrong incentives by paying none of the extra expense of using an expensive procedure.
2.	Carpenter	1988	Book chapter	Perspectives of industry, the physicians and government of technological innovation	The survival of the US biomedical industry relies on three key elements: the way risks of using products and risks associated with innovation are dealt with; the responsibilities of manufacturers, regulators and users; and the need for the informed consent of the user.
3.	Bartlett Foote	1988	Book chapter	Product liability and regulation of medical devices	Product liability and regulation are two public policies that have emerged in response to the growing availability of medical devices. This paper presents an analytical framework to appraise the strengths and weaknesses of existing policies. Tort systems should achieve a combination of goals, including deterrence and redress, compensation, and efficiency.
4.	Cuthrell	1996	Professional journal article	Management of equipment failures and the Safe Medical Devices Act (SMDA)	A nurse must become familiar with equipment function, appropriate settings, limitations, alarm settings, and intended use. Nurses must assume responsibilities for the management and implementation of the SMDA (tracking process, operator errors and reporting mechanisms).
5.	Emergency Care Research Institute (ECRI)	1997	ECRI newsletter	Changes in medical equipment service market	Clinical engineering departments should become more active participants in the medical technology arena.
6.	Gelijns	1994	Research journal article	Dynamics of technological change in medicine	Technological change may rise health care costs through: intensity of use of existing technologies, introduction of new technologies, and expanded application of new technologies. One must tie the results of assessments more strongly to clinical decisions directly (feedback to providers) or indirectly (regulatory mechanisms).
7.	Hamill	1997	Professional journal article	Home medical equipment services providers (HMESP)	HMESP offer: intake, communication with referral and doctor, determination of medical necessity, patient and home evaluation, communication with other agencies, medical documentation, delivery, patient and caregiver education, equipment maintenance, cleaning, tracking and pick-up, and billing and collections.
8.	Moxley	1988	Book chapter	Hospital perspective on technological innovation	The single most important characteristic of 20th century US medicine is its capacity for scientific improvement and technological adaptation. Public and private sector should work together to support advances in science and technology.
9.	Perry	1988	Book chapter	Conflict between cost containment and access to medical innovations	Cost-containment strategies should redirect funds away from unnecessary and ineffective care and toward effective medical care. Governments, insurers, manufacturers and providers should embrace common objectives and support medical technology assessment.

Medical equipment and R&D issues (cont'd)

N°	1ST AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
10.	Romeo	1988	Book chapter	Private investments in medical innovations	Private investments will tend to be directed toward making profits. As private firms respond to market signals, little investment flows when signals are weak. In addition, market or government signals in health care may not reflect accurately social values or may not stimulate a balanced mix of investments. Government intervention may thus be required.
11.	Thier	1988	Book chapter	New medical devices	Physicians should develop a framework for technological innovation, ranking prevention and screening higher than therapeutic interventions. Selecting the most appropriate use for new technology in support of health, and not protecting physicians from liability or enabling a manufacturer to develop a new device, should be the common objective of medicine, engineering and industry.
12.	Watrous	1993	Professional journal article	Home care equipment management	The use of a Total Quality Management model enhances equipment selection process, management of equipment-related data and standardization of equipment delivery contracts. The team applying this model increased its efficiency by better data management, decreased discharge delays and improved continuity of care.
13.	Zarbock	1997	Interview	Home medical equipment suppliers' role	Home medical equipment suppliers provide several services (regulatory advocates, physician education, patient support) that are not sufficiently recognized.

TABLE A-19

Other (costs, methodological aspects)

N°	1ST AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
1.	Aiken	1997	Research journal article	Measurement of outcomes of organizational change	Organizational research may contribute to outcomes research. A theoretical framework is presented and methodological issues are explored.
2.	Arno	1995	Book chapter	Economic impact of high-tech home care	The availability of reimbursement for high-tech home care through public and private insurance programs and early discharge from hospitals have fuelled the growth of what appears to be a profitable industry. The cost-effectiveness of home care is called into question by high prices that bear little relationship to costs.
3.	Bronstein	1996	Research journal article	Patient's choice for ambulatory care	Review of Medicaid claims data from the state of Alabama showed that an increased office-based provider availability must be coupled with improved access for new, remote, and very low income families if Medicaid clients are to be expected to shift their choice of site for ambulatory care.
4.	Brooker	1995	Research journal article	Observational studies into the quality of institutional care for elderly people with dementia	Observational methods often attempt to quantify type and levels of residents' activity. Recent techniques (quality of interactions scale and dementia care mapping) consider the quality as well as the quantity of activity. Their practical use in improving standards is yet to be proven.
5.	Cullen	1998	Professional journal article	Perceptions of students nurses on home care nurses	Student nurses gained valuable knowledge through observational home care experiences. This is a vital learning in context experience.
6.	Dougherty	1998	Research journal article	Economic evaluation of home care for children with diabetes	This randomized controlled trial (RCT) examined the health and cost effects of home care vs. traditional inpatient care. 63 children were randomized and followed for 24 months. Social costs were only $48 higher with home care. The increased costs of health care services with home care ($768) were largely offset by parental cost savings ($720).
7.	Feldman	1996	Research journal article	Cost savings and outcomes of the Medicaid-funded home care for the frail elderly and disabled	Based on pre-post design, this study indicates that cluster care reduced costs by 10% and is associated with a significant decline in satisfaction. For the more vulnerable, low-cost interventions that might augment service and improve outcomes without reverting to traditional one-on-one care are recommended.
8.	Hindler	1996	Research journal article	Perceptions of drug misusers of general practitioner care	Semi-structured interviews with drug users attending five different treatments services revealed that the relationship between doctor and patient was not always easy or productive. The general practitioner's role should be clarified and educational opportunities should be provided.
9.	Kaplan	1996	Research journal article	Characteristics of physicians with participatory decision-making styles	A questionnaire survey of patients and physicians revealed that participatory decision-making is influenced by physicians' background, training, practice volume and professional autonomy. Cost-containment strategies that reduce time with patients may result in suboptimal patient outcomes since decision-making style is related to patient satisfaction and loyalty to the physician.
10.	Kitwood	1992	Research journal article	Dementia care mapping as a new approach to the evaluation of dementia care	The DCM method allows a better understanding of dementia and care provision. DCM shows that effective dementia care compensates for an individual's handicaps by making practical provision and deals emphatically with a range of emotional needs.

Other (costs, methodological aspects) (cont'd)

N°	1ST AUTHOR	YEAR	TYPE	FOCUS	CONCLUSIONS
11.	Levy	1993	Research journal article	Economic impact of the use of technology in ambulatory practice	Based on opinion surveys, this study shows that despite a steady increase in prescription of technological acts the number of physicians owning high-tech devices is low. The specialty and the pace of obsolescence influence physicians' investment behaviour.
12.	Mor	1993	Research journal article	Physician use among cancer patients	Patients with advanced cancer who received outpatient chemotherapy reported seeing an average of three physicians and average of 15 times in 3 months. Patients without a regular physician had a less concentrated pattern of visits than did those with a regular physician. Demographic and disease characteristics were only moderately associated with visit volume.
13.	Rosenzweig	1995	Book chapter	Trends in home care entitlements and benefits	Without sufficient uniform funding available throughout the states, large numbers of the frail elderly and disabled will remain dependent on friends, family and privately hired home care.
14.	Rosser	1996	Professional journal article	Differences between diagnostic approaches of primary care physicians and specialists	Patient-focused family physicians, compared to disease-focused specialists, order fewer tests and procedures, sustain a partnership with patients, lead to less costly health care and deal with greater diagnostic uncertainty.
15.	Soderstrom	1999	Research journal article	Review of health and cost effects of home care	Four studies evaluating home care for 5 conditions (hip fracture, hip replacement, COPD, hysterectomy and knee replacement) with high internal validity were reviewed. Compared with hospital care, home care had no notable effects on patients' or caregivers' health. Social costs were unaffected for hip and knee replacement, and higher for COPD and hysterectomy. Effects on health system costs were mixed, with cost savings for hip fracture and higher costs for hip and knee replacement.
16.	Tang	1995	Research journal article	Methods for assessing information needs of clinicians in ambulatory care	Better understanding of health care team's information needs should improve the development of appropriate information technology. Clinicians in ambulatory care need the following functional requirements: access to problem lists and medications, patient-specific instructions and education, and tools for health care team communications.

REFERENCES

Adachi K, Lubben JE, Tsukada N. Expansion of formalized in-home services for Japan's aged. J Aging Soc Policy 1996;8(2-3):147-59.

Aiken LH, Sochalski J, Lake ET. Studying outcomes of organizational change in health services. Med Care 1997;35(Suppl 11):NS6-18.

Aitken MJ. Matching models to environments. A planning guide to the selection of pediatric home care models. Home Healthc Nurse 1989;7(2):13-21.

Akrich M. The description of technical objects. In: Bijker WE, Law J, ed. Shaping technology / building society: studies in sociotechnical change. Cambridge, MS: MIT Press; 1994.

Allen LVJ. Drugs, devices and delivery considerations in parenteral pharmaceutical care, or, what are they doing with our drugs? PDA J Pharm Sci Technol 1995;49(6):306-8.

Allman RM, Laprade CA, Noel LB, Walker JM, Moorer CA, Dear MR, Smith CR. Pressure sores among hospitalized patients. Ann Intern Med 1986;105(3):337-42 [cited by Pousada, 1995].

Allwood CM, Kalen T. User-competence and other usability aspects when introducing a patient administrative system: a case study. Interact Comput 1993;5(2):167-91.

Altman SH. Impact of the changing medical payment system on technological innovation and utilization. In: Ekelman KB, ed. New medical devices. Invention, development, and use. Washington, DC: National Academy Press; 1988: 93-103.

American Association of Retired Persons. PERS (personal emergency response system). Product report. In: Kaye LW, ed. New developments in home care services for the elderly: innovations in policy, program, and practice. New York, NY: The Haworth Press; 1995.

American Medical Association. Educating physicians in home health care. Council on Scientific Affairs and Council on Medical Education. JAMA 1991;265(6):769-71 [cited by Kapp, 1995a].

Anderson M, Parent K, Canadian Association of Retired Persons. Putting a face on home care: CARP's report on home care in Canada 1999. Kingston, ON: Queen's Health Policy Research Unit, Queen's University; 1999.

Arno PS, Bonuck K, Padgug R. The economic impact of high-tech home care. In: Arras JD, Porterfield WH, Porterfield LO, ed. Bringing the hospital home. Ethical and social implications of high-tech home care. Baltimore, MD: The Johns Hopkins University Press; 1995: 220-34.

Arras JD, Dubler NN. Introduction: ethical and social implications. In: Arras JD, Porterfield WH, Porterfield LO, ed. Bringing the hospital home. Ethical and social implications of high-tech home care. Baltimore, MD: The Johns Hopkins University Press; 1995: 1-34.

Arundel C, Glouberman S, Canadian Policy Research Networks. An analysis of blockage to the effective transfer of clients from acute care to home care (Substudy 15). Ottawa: CPRN; 2001. Available: http://www.homecarestudy.com/reports/full-text/substudy-15-final_report.pdf (accessed August 31, 2004).

Association des CLSC et des CHSLD du Québec. Guide d'accès aux fournitures et aides techniques. Montréal: Association des CLSC et des CHSLD du Québec; 1998a.

Association des CLSC et des CHSLD du Québec. Les changements dans le secteur de l'aide à domicile. Montréal: Association des CLSC et des CHSLD du Québec; 1998b.

Association des CLSC et des CHSLD du Québec. Une transformation à consolider... une réforme à continuer. Montréal: Association des CLSC et des CHSLD du Québec; 1998c.

Association des hôpitaux du Québec (AHQ). Modèles d'organisation des services ambulatoires dans un centre hospitalier. Montréal: AHQ; 1997.

Association féminine d'éducation et d'action sociale, Côté D, Gagnon É, Gilbert C, Guberman N, Saillant F, et al. Who will be responsible for providing care? The impact of the shift to ambulatory care and of social economic policies on Quebec women. Ottawa: Status of Women Canada; 1998.

Baldock J. The national context of social innovation. England and Wales. In: Kraan R, Baldock J, Davies B, et al., ed. Care for the elderly. Significant innovations in three European countries. Frankfurt, Germany: Campus Verlag; 1991: 45-69.

Baldock J, Evers A. Local innovations strengthening home-based care: on overview of major developments and significant examples. Concluding remarks on the significance of the innovations reviewed: their implications for social change. In: Kraan R, Baldock J, Davies B, et al., ed. Care for the elderly. Significant innovations in three European countries. Frankfurt, Germany: Campus Verlag; 1991: 186-202 [cited by Monk et Cox, 1995].

Baldock JTC, Knapen M. The national context of social innovation. The Netherlands. In: Kraan R, Baldock J, Davies B, et al., ed. Care for the elderly. Significant innovations in three European countries. Frankfurt, Germany: Campus Verlag; 1991: 7-27.

Balinsky W. Home care. Current problems and future solutions. San Francisco, CA: Jossey-Bass Publishers; 1994.

Bartlett Foote S. Coexistence, conflict, and cooperation: public policies toward medical devices. J Health Polit Policy Law 1986;11(3):501-23.

Bartlett Foote S. Product liability and medical device regulation. In: Ekelman KB, ed. New medical devices. Invention, development, and use. Washington, DC: National Academy Press; 1988: 73-92.

Bastian H. Speaking up for ourselves. The evolution of consumer advocacy in health care. Int J Technol Assess Health Care 1998;14(1):3-23.

Battista RN, Lance JM, Lehoux P, Régnier G. Health technology assessment and the regulation of medical devices and procedures in Quebec. Synergy, collusion, or collision? Int J Technol Assess Health Care 1999;15(3):593-601.

Bean CA. High-tech homecare infusion therapies. Crit Care Nurs Clin North Am 1998;10(3):287-303.

Beaulieu MD, Blais MJ, Conseil d'évaluation des technologies de la santé du Québec. Exploration et détermination des priorités d'évaluation dans les services ambulatoires. Montréal: CETS; 1996 (96-4).

Becker AE. 21st century home care: back to the future. Home health care: new opportunities and directions: proceedings of the Insight conference, January 30-31, 1997. Toronto, ON: Insight Press; 1997: 33-42.

Béland F, Bergman H. Home care, continuing care and medicare: a Canadian model or innovative models for Canadians? Healthc Pap 2000;1(4):38-45, 109-12.

Benjamin AE, Matthias R, Franke TM. Comparing consumer-directed and agency models for providing supportive services at home. Health Serv Res 2000;35(1 Pt 2):351-66.

Benson JA, Michelman JE, Radjenovic D. Using information technology strategically in home care. Home Healthc Nurse 1996;14(12):977-83.

Berge JA, Gramstad L, Grimnes S. A simplified concept for controlling oxygen mixtures in the anaesthetic machine–better, cheaper and more user-friendly? Acta Anaesthesiol Scand 1995;39(4):563-7.

Bérubé M. Les services ambulatoires hospitaliers... dans le continuum des services de santé physique. Montréal: Régie régionale de la santé et des services sociaux de Montréal-Centre; 1996.

Biggert RA, Watkins JL, Cook SE. Home infusion service delivery system model: a conceptual framework for family-centered care in pediatric home care delivery. J Intraven Nurs 1992;15(4):210-8.

Boling PA, Keenan JM, Schwartzberg J, Retchin SM, Olson L, Schneiderman M. Reported home health agency referrals by internists and family physicians. J Am Geriatr Soc 1992;40(12):1241-9.

Boudreau TJ, Brunet J, Deschênes JC. Le système sociosanitaire québécois: bilan et perspectives. Québec: MSSS; 1997.

Bowers G, Adams J. Documentation on trial: nine ways to protect your agency. Caring 1999;18(6):12-3, 15.

Bows J. Opening address. In: Allen I, Cameron A, Perkins IE. Stimulating provision by the independent sector. London, England: Policy Studies Institute; 1999: 1-6.

Brahams D. The legal implications of the provision of health information. In: Griffin J, ed. Health information and the consumer. London, England: Office of Health Economics; 1995: 31-40.

Branger PJ, Van Oers RJ, Van der Wouden JC, van der Lei J. Laboratory services utilization: a survey of repeat investigations in ambulatory care. Neth J Med 1995;47(5):208-13.

Brent NJ. High-tech care and medical devices: the Safe Medical Devices Act of 1990. Home Healthc Nurse 1992;10(3):11-2.

Bronstein JM, Johnson VA. Patient's choice of hospital of office for Medicaid ambulatory care in Alabama. Med Care 1996;34(4):348-60.

Bronzino JD, Smith VH, Wade ML. Medical technology and society: an interdisciplinary perspective. Cambridge, MS: MIT Press; 1990.

Brooker D. Looking at them, looking at me. A review of observational studies into the quality of institutional care for elderly people with dementia. Journal of Mental Health 1995;4:145-56.

Brooker DJ. Issues in user feedback on health services for elderly people. Br J Nurs 1997;6(3):159-62.

Brooks D. Electronic tracking: new applications for tried-and-true technology. Caring 1998;17(12):50-1.

Brown AR, Mulley GP. Do it yourself: home-made aids for disabled elderly people. Disabil Rehabil 1997;19(1):35-7.

Brown KK. Innovation where it counts: in the home. Adv Pract Nurs Q 1996;1(4):28-35.

Burman ME. The organizational environments and services of VNAs and hospital-based home health care agencies. Res Nurs Health 1992;15(4):285-94.

Calico F. Home health moving toward 'high touch, high tech'. Health Manag Technol 1996;17(11):22-5, 27.

Callon M. Society in the making: the study of technology as a tool for sociological analysis. In: Bijker WE, Hughes TPE. The social construction of technological systems. Cambridge, MS: MIT Press; 1989: 83-106.

Campbell T, Lunn D. Intravenous therapy: current practice and nursing concerns. Br J Nurs 1997;6(21):1218-20, 1222, 1224-8.

Canadian Home Care Association (CHCA). Home care in Alberta: a portrait. Ottawa: ACSSD; 1998a.

Canadian Home Care Association (CHCA). Home care in British Columbia: a portrait. Ottawa: ACSSD; 1998b.

Canadian Home Care Association (CHCA). Home care in Manitoba: a portrait. Ottawa: ACSSD; 1998c.

Canadian Home Care Association (CHCA). Home care in Newfoundland: a portrait. Ottawa: ACSSD; 1998d.

Canadian Home Care Association (CHCA). Home care in Northwest Territories: a portrait. Ottawa: ACSSD; 1998e.

Canadian Home Care Association (CHCA). Home care in Nova Scotia: a portrait. Ottawa: ACSSD; 1998f.

Canadian Home Care Association (CHCA). Home care in Ontario: a portrait. Ottawa: ACSSD; 1998g.

Canadian Home Care Association (CHCA). Home care in Prince Edward Island: a portrait. Ottawa: ACSSD; 1998h.

Canadian Home Care Association (CHCA). Home care in Saskatchewan: a portrait. Ottawa: ACSSD; 1998i.

Canadian Home Care Association (CHCA). Maintien à domicile au Québec: un portrait. Ottawa: ACSSD;

1998j.

Canadian Institute for Health Information (CIHI). Health care in Canada 2003. Ottawa: CIHI; 2003a. Available: http://secure.cihi.ca:80/cihiweb/dispPage.jsp?cw_page=AR43_2003toc_e (accessed September 2, 2004).

Canadian Institute for Health Information (CIHI). The next essential service. Home care. Phase 2. March 2003. Ottawa: CIHI; 2003b. Available: http://secure.cihi.ca/cihiweb/en/downloads/indicators_homecare_updateMar2003_e.pdf (accessed September 2, 2004).

The Caregiver. The newsletter of Caregiver network™. Toronto, ON: CNI; Fall 1999.

Carpenter PF, Samuel FE, Fineberg HV, Russell LB. Perspectives of industry, the physicians, and government. In: Ekelman KB, ed. New medical devices. Invention, development, and use. Washington, DC: National Academy Press; 1988: 138-63.

Carroll-Johnson RM. Revisiting the high-tech/high-touch dilemma. Oncol Nurs Forum 1998;25(8):1299.

Carruth AK, Steele S, Moffett B, Rehmeyer T, Cooper C, Burroughs R. The impact of primary and modular nursing delivery systems on perceptions of caring behavior. Oncol Nurs Forum 1999;26(1):95-100.

Catanzaro J, Serembus JF. High-tech wound and ostomy care in the home setting. Crit Care Nurs Clin North Am 1998;10(3):327-38.

Centre de recherche en droit privé et comparé du Québec (CRDPC). Développement d'un programme de gestion des accidents thérapeutiques et des événements malencontreux reliés à la prestation de soins de santé. Québec: CRDPC; 1997.

Cerra FB, Kaplan EL, Schwarzenberg SJ, Soltis R, Twiggs L. A managed care model for home infusion therapy. Am J Med Qual 1995;10(2):93-9.

Champagne F, Contandriopoulos AP, Rodriguez R. Centres ambulatoires: typologie, avantages et inconvénients. Montréal: Groupe de recherche interdisciplinaire en santé, Université de Montréal; 1997 (R97-06).

Chan JS, Filippone AM. High-tech pediatric home care: a collaborative approach. Caring 1998;17(5):30-6.

Cherin DA, Huba GJ, Brief DE, Melchior LA. Evaluation of the transprofessional model of home health care for HIV/AIDS. Home Health Care Serv Q 1998;17(1):55-72.

City of New York. Department of Consumer Affairs. Making a killing on AIDS: home health care and pentamidine. New York, NY: Department of Consumer Affairs; 1991 [cited by Arras and Dubler, 1995].

Coleman BJ. European models of long-term care in the home and community. Int J Health Serv 1995;25(3):455-74.

Collège des médecins du Québec (CMQ). Rapport du sondage sur le virage ambulatoire. Montréal: CMQ; 1996.

Collège des médecins du Québec (CMQ). Commission sur l'exercice de la médecine des années 2000. Document de consultation. Montréal: CMQ; 1997.

Colvez A, Ridez S. Déterminants objectifs et subjectifs du bénéfice de l'aide ménagère pour le maintien à domicile des personnes âgées. Rev Epidemiol Santé Publique 1996;44(2):163-72.

Conseil consultatif sur les aides technologiques (CCAT). Attribution d'aides technologiques aux personnes âgées: état de la situation. Québec: CCAT; 1994.

Conseil d'évaluation des technologies de la santé du Québec (CETS). Exploration et détermination des priorités d'évaluation dans les services ambulatoires. Montréal: CETS; 1996 (CETS 96-4).

Conseil d'évaluation des technologies de la santé du Québec (CETS). Domiciliary long-term oxygen therapy for chronic respiratory insufficiency. Montréal: CETS; 1990 (CETS 3).

Conseil de la science et de la technologie (CST). Urgence technologie : pour un Québec audacieux, compétitif et prospère: avis à la ministre de l'enseignement supérieur et de la science. Québec: Les Publications du Québec; 1993.

Côté MH, Deschamps P. REMEDHOS: the development of a medical and hospital liability database in Quebec. Med Law 1992;11(5-6):363-81.

Council on Scientific Affairs and Council on Medical Education. Educating physicians in home health care. JAMA 1991;265(6):769-71.

Coyte P. Home care: potentials and problems. Conference diagnosis and solutions: building consensus for health care reform in Canada, Montréal, Qc, February 14-16, 2003. Montréal: McGill Institute for the Study of Canada; 2002. Available: http://www.misc-iecm.mcgill.ca/HCC/workshop10.pdf (accessed September 15, 2004).

Coyte P, Young W. Regional variations in the use of home care services in Ontario, 1993-1995. CMAJ 1999;161(4):376-80.

Cranswick K. Canada's caregivers. In: Statistics Canada. Canadian social trends. Ottawa: Statistics Canada; 1997.

Creel J. Cancer care at home: past, present, and future. Caring 1996;15(11):24-6, 29.

Cullen JA. How students nurses see home healthcare nurses today. Home Healthc Nurse 1998;16(2):74-9.

Cuthrell P. Managing equipment failures: nursing practice requirements for meeting the challenges of the Safe Medical Devices Act. J Intraven Nurs 1996; 19(5):264-8.

Dahlof CG, Boes-Hansen S, Cederberg CG, Hardebo JE, Henriksson A. How does sumatriptan nasal spray perform in clinical practice? Cephalalgia 1998;18(5):278-82.

Dansky KH, Milliron M, Gamm L. Understanding hospital referrals to home health agencies. Hosp Health Serv Adm 1996;41(3):331-42.

Darbyshire P. User-friendliness of computerized information systems. Comput Nurs 2000;18(2):93-9.

Daveluy C, Institut de la statistique du Québec. Enquête sociale et de santé 1998. 2nd ed. Québec: ISQ; 2001.

Davis JH. Total parenteral nutrition (TPN) at home: prototype high-tech home care nursing. Gastroenterol Nurs 1996;19(6):207-9.

Davitt JK, Kaye LW. High-tech home health care: administrative and staff perspectives. Home Health Care Serv Q 1995;15(4):49-66.

Devins GM, Binik YM. Psychosocial impact of chronic life-threatening illness: lessons from end-stage renal disease. Ottawa: Health Canada; 1995 (NHRDP: 6609-1232).

Di Pisa F, Mastrangelo D, Hadjistilianou T, Squitieri N, Rinaldo F, Donoso L, Frezzotti R. Design and implementation of a relational database used in the management of patients with retinoblastoma. Comput Biomed Res 1997;30(4):273-89.

Diehm SL. High-tech home care solutions. Contin Care 1995;14(1):37, 42.

Dodier N. L'expertise médicale: essai de sociologie sur l'exercice du jugement. Paris: Métailié; 1993.

Doherty AM. Mobilization of the interdisciplinary critical care team at home and abroad. Crit Care Nurs Clin North Am 1998;10(3):369-76.

Dougall A, Russell A, Rubin G, Ling J. Rethinking patient satisfaction: patient experiences of an open access flexible sigmoidoscopy service. Soc Sci Med 2000;50(1):53-62.

Dougherty G. When should a child be in the hospital? A. Frederick North, Jr, MD, revisited. Pediatrics 1998;101(1 Pt 1):19-24.

Dougherty GE, Soderstrom L, Schiffrin A. An economic evaluation of home care for children with newly diagnosed diabetes: results from a randomized controlled trial. Med Care 1998;36(4):586-98.

Downey GL, Lucena JC. Engineering studies. In: Jasanoff S, Marke GE, Petersen JC, Pinch T, ed. Handbook of science and technology studies. Thousand Oaks, CA: Sage publications; 1994: 167-88.

Dumont-Lemasson M, Donovan C, Wylie M, Federal-Provincial-Territorial Advisory Committee on Health Services Working Group on Continuing Care. Provincial and territorial home care programs: a synthesis for Canada. Ottawa: Health Canada; 1999. Available: http://www.hc-sc.gc.ca/english/pdf/home_round/homecr-e.pdf (accessed August 31, 2004).

Dunning M, Needham G. But will it work doctor? Conference on users of health services, King's Fund Centre, November 9, 1993. Report. London, England: Health Information Consortium; 1994.

Dunning M, Needham G, Weston S, Health Information Consortium. But will it work doctor? Report of a conference about promoting and supporting patient choice by making evidence about the effectiveness of health care accessible to health service users, Northampton, May 22-23, 1996. London, England: But Will it Work, Doctor? Group; 1997.

Eaton B. Why we do not make housecalls. Can Fam Physician 2000;(46):1945-7, 1957-9.

Ebersole P. Trends in care delivery models. Geriatr Nurs 1998;19(1):6-7.

Elkan R, Kendrick D, Hewitt M, Robinson JJ, Tolley K, Blair M, et al. The effectiveness of domiciliary health visiting: a systematic review of international studies and a selective review of the British literature. Health Technol Assess 2000;4(13):i-v, 1-339.

Emergency Care Research Institute (ECRI). Evaluation: ambulatory infusion pumps. Health Devices 1991;20(9):324-58.

Emergency Care Research Institute (ECRI). Evaluation: general-purpose infusion pumps. Health Devices 1997;26(2):36-75.

Emmanuel LL. Advance directives for medical care. A case for greater use. N Eng J Med 1991;324(1):889-95 [cited by Kaye et Davitt, 1998].

Erickson GP. Clinical pearls for home health nursing: recollections from an oral history. Home Healthc Nurse 1996;14(11):906-13.

Evers A. Introduction. In: Kraan R, Baldock J, Davies B, et al., ed. Care for the elderly. Significant innovations in three European countries. Frankfurt, Germany: Campus Verlag; 1991: 1-6.

Fagerhaugh S, Strauss A, Suczek B, Wiener C. Chronic illness, medical technology, and clinical safety in the hospital. Research in the sociology of health care. Volume 4. Greenwich, CT: JAI Press; 1986: 237-70.

Fauroux B, Howard P, Muir JF. Home treatment for chronic respiratory insufficiency: the situation in Europe in 1992. The European Working Group on Home Treatment for Chronic Respiratory Insufficiency. Eur Respir J 1994;7(9):1721-6.

Feder BJ. Where the boom is in health care. New York Times 1991 [cited by Arras et Dubler, 1995].

Feldman PH, Latimer E, Davidson H. Medicaid-funded home care for the frail elderly and disabled: evaluating the cost savings and outcomes of a service delivery reform. Health Serv Res 1996;31(4):489-508.

Fetterman T. My disability made me do it. Technol Disab 1997;7(1):73-6.

Fiesta J. Who's liable in equipment cases? Nurs Manage 1999;30(4):12-3, 15.

Forrest CB, Starfield B. The effect of first-contact care with primary care clinicians on ambulatory health care expenditures. J Fam Pract 1996;43(1):40-8.

Forster T. The independent provider in home care. In search of a reasonable resolution. Caring 1992;11(4):40-2.

Freed PE, Drake VK. Mandatory reporting of abuse: practical, moral, and legal issues for psychiatric home healthcare nurses. Issues Ment Health Nurs 1999;20(4):423-36.

Friedman MM. Risk management strategies for home transfusion therapy. J Intraven Nurs 1997;20(4):179-87.

Gabel LL, Lucas JB, Westbury RC. Why do patients continue to see the same physician? Fam Pract Res J 1993;13(2):133-47.

Gardner DM, Shulman KI, Walker SE, Tailor SA . The making of a user friendly MAOI diet. J Clin Psychiatry 1996;57(3):99-104.

Gelijns A, Rosenberg N. The dynamics of technological change in medicine. Health Aff (Millwood) 1994;13(3):28-46.

Gibbs S. Medicines and the role of patient information leaflets. In: Griffin J, ed. Health information and the consumer. London, England: Office of Health Economics; 1995: 25-30.

Giordano BP. High-tech health care is great, but our first duty is to do no harm. AORN J 1995;61(2):314, 316.

Goode MA, Gums JG. Therapeutic drug monitoring in ambulatory care. Ann Pharmacother 1993;27(4):502-5.

Gorski LA. Patient education in high-tech home care. Caring 1995;14(5):22-8.

Griffin J. Introduction. In: Griffin J, ed. Health information and the consumer. London, England: Office of Health Economics; 1995: 1-7.

Grin JM, McCabe EJ, White WB. Management of hypertension after ambulatory blood pressure monitoring. Ann Intern Med 1993;118(11):833-7.

Haas S, Gold C. Supervision of unlicensed assistive workers in ambulatory settings. Nurs Econ 1997;15(1):57-9.

Hamill CT. Who are home medical equipment services providers? Home Care Provid 1997;2(4):197-8.

Hamill CT. Medical equipment services industry: the time is now. Best Pract Benchmarking Healthc 1996;1(6):290-6.

Handy J. Alternative organisational model in home care. In: Kaye LW, ed. New developments in home care services for the elderly: innovations in policy, program, and practice. New York, NY: The Haworth Press; 1995: 49-66.

Harrison GMJ, Mitchell MB. The medical and social outcome of 200 respirator and former respirator patients on home ocre. Arch Phys Med Rehabil 1961;42:590-8 [cited by Okun, 1995].

Hartley RM, Charlton JR, Harris CM, Jarman B . Patterns of physicians' use of medical resources in ambulatory settings. Am J Public Health 1987;77(5):565-7.

Health Canada. Canada Health Act. Annual report 1998-1999. Ottawa: Health Canada; 2000a. Available: http://www.hc-sc.gc.ca/medicare/Documents/CHA9899.pdf (accessed September 2, 2004).

Health Canada. Canada Health Act. Ottawa: Health Canada; 2000b.

Health Canada. Report on the national roundtable on home and community care. Ottawa: Health Canada; 1999. Available: http://www.hc-sc.gc.ca/homecare/english/rt1.html (accessed September 2, 2004).

Health Canada. Misleading advertisement of home use medical devices. Ottawa: Health Canada; 1998a (It's your health). Available: http://www.hc-sc.gc.ca/hpb-dgps/therapeut/zfiles/english/publicat/iyh_mislead.html (accessed August 31, 2004).

Health Canada. Medical devices bulletin. Ottawa: Health Canada; 1998b.

Health Canada. Public home care expenditures, 1975-76 to 1997-98. Ottawa: Health Canada; 1998c. Available: http://www.hc-sc.gc.ca/english/care/expenditures/homecare.html (accessed September 2, 2004).

Health Canada. Office of Health and the information highway. Tele-homecare: an overview–background paper for discussion. Ottawa: Health Canada; 1998d. Available: http://www.hc-sc.gc.ca/ohih-bsi/pubs/1998_tele/tele_e.html (accessed September 2, 2004).

Health Canada. Medical devices regulations. Ottawa: Health Canada; 1997 (JUS-97-623-01).

Health Services Utilization and Research Commission (HSURC). The impact of preventive home care and seniors housing on health outcomes. Saskatoon, SK: HSURC; 2000 (Summary report 14).

Health Services Utilization and Research Commission (HSURC). Measuring the effectiveness of home care. A rigorous review of the literature. Saskatoon, SK: HSURC; 1996a (Background paper 1).

Health Services Utilization and Research Commission (HSURC). The cost-effectiveness of home care. A rigorous review of the literature. Saskatoon, SK: HSURC; 1996b (Background paper 2).

Heathfield H, Pitty D, Hanka R. Evaluating information technology in health care: barriers and challenges. BMJ 1998;316(7149):1959-61.

Hébert R, Dubuc N, Buteau M, Roy C, Desrosiers J, Bravo G, et al. Services requis par les personnes âgées en perte d'autonomie: évaluation clinique et estimation des coûts selon le milieu de vie. Québec: MSSS; 1997 (Études et analyses series, no. 33).

Heitman E. Ethical issues in technology assessment. Conceptual categories and procedural considerations. Int J Technol Assess Health Care 1998;14(3):544-66.

Helberg JL. Factors influencing home care nursing problems and nursing care. Res Nurs Health 1993;16(5):363-70.

Hindler C, King M, Nazareth I, Cohen J, Farmer R, Gerada C. Characteristics of drug misusers and their perceptions of general practitioner care. Br J Gen Pract 1996;46(404):149-52.

Hollander M. Overview of home care clients. Victoria, BC: National Evaluation of the Effectiveness of Health Care; 2002 (Substudy 7). Available: http://www.homecarestudy.com/reports/fulltext/substudy-07-final_report.pdf (accessed September 2, 2004).

Hollander M, Chappell N. Final report of the national evaluation of the cost-effectiveness of home care. Synthesis report. A report prepared for the Health Transition Fund. Victoria, BC: National Evaluation of the Effectiveness of Health Care, Center of Aging, University of Victoria; 2002. Available: http://www.homecarestudy.com/reports/full-text/synthesis.pdf (accessed September 14, 2004).

Hollander M, Anderson M, Béland F, Havens B, Keefe J, Parent K, Ritter R. The identification and analysis of incentives and disincentives and cost-effectiveness of various funding approaches for continuing care. Victoria, BC: Hollander Analytic Services; 2000. Available: http://www.hollanderanalytical.com/downloads/id-final.pdf (accessed September 2, 2004).

Howell D, Jackson J. Making cancer bearable: the Interlink Community Cancer Nurses model of supportive care. Can Oncol Nurs J 1998;8(4):222-8.

Huba GJ, Cherin DA, Melchior LA. Retention of clients in service under two models of home health care for HIV/AIDS. Home Health Care Serv Q 1998;17(3):17-26.

Husted GL, Miller MC, Brown B. Test of an educational brochure on advance directives designed for well-elderly people. J Gerontol Nurs 1999;25(1):34-40.

IMPACT Recherche. Étude sur les perceptions et les opinions de la population face au virage ambulatoire (2^e vague). Québec: IMPACT Recherche; 1996 (Dossier 15-4139-H).

Jamison M. Chronic illness management in the year 2005. Nurs Econ 1998;16(5):246-53.

Johansson L, Thorslund M. The national context of social innovation–Policy framework and major reforms in care for the elderly. Sweden. In: Kraan R, Baldock J, Davies B, et al., ed. Care for the elderly. Significant innovations in three European countries. Frankfurt, Germany: Campus Verlag; 1991: 28-44.

Joule N. Involving users of health care services: moving beyond lip service. Qual Health Care 1993;2(4):211-2.

Joy M. Death in the home: the doctor's responsibility. J Long Term Home Health Care 1998;17(4):2-8.

Kafka BA. Home care and the disability community. Two factions with one goal. Caring 1998;17(7):26-7, 29.

Kane RA. High-tech home care in context : organizations, quality, and ethical ramifications. In: Arras JD, Porterfield WH, Porterfield LO, ed. Bringing the hospital home. Ethical and social implications of high-tech home care. Baltimore, MD: The Johns Hopkins University Press; 1995: 197-219.

Kangas S, Kee CC, McKee-Waddle R. Organizational factors, nurses' job satisfaction, and patient satisfaction with nursing care. J Nurs Adm 1999;29(1):32-42.

Kaplan SH, Greenfield S, Gandek B, Rogers WH, Ware JE. Characteristics of physicians with participatory decision-making styles. Ann Intern Med 1996;124(5):497-504.

Kapp MB. Legal and ethical issues in home-based care. In: Kaye LW, ed. New developments in home care services for the elderly: innovations in policy, program, and practice. New York, NY: The Haworth Press; 1995a: 31-45.

Kapp MB. Problems and protocols for dying at home in a high-tech environment. Introduction: ethical and social implications of high-tech home care. In: Arras JD, Porterfield WH, Porterfield LO, ed. Bringing the hospital home. Ethical and social implications of high-tech home care. Baltimore, MD: The Johns Hopkins University Press; 1995b: 180-96.

Kaunitz AM. Reappearance of the intrauterine device: a 'user-friendly' contraceptive. Int J Fertil Womens Med 1997;42(2):120-7.

Kaye LW. New developments in home care services for the elderly: innovations in policy, program, and practice. New York, NY: The Haworth Press; 1995.

Kaye LW, Davitt JK. Comparison of the high-tech service delivery experiences of hospice and non-hospice home health providers. Hosp J 1998;13(3):1-20.

Kaye LW, Davitt JK. Provider and consumer profiles of traditional and high-tech home health care: the issue of differential access. Health Soc Work 1995a;20(4):262-71.

Kaye LW, Davitt JK. Importation of high technology services into the home. In: Kaye LW, ed. New developments in home care services for the elderly: innovations in policy, program, and practice. New York, NY: The Haworth Press; 1995b: 67-94.

Kelson M. User involvement in clinical audit: a review of developments and issues of good practice. J Eval Clin Pract 1996;2(2):97-109.

Kendix M. Provision of home dialysis by freestanding renal dialysis facilities. Health Care Financ Rev 1995;17(2):105-22.

Kitwood T, Bredin K. A new approach to the evaluation of dementia care. J Advances Health Nurs 1992;1(5):41-60.

Kjervik DK, Badzek L. Legal considerations at the end of life. ANNA J 1998;25(6):593-7.

Koepke MD, Nyman JA, Koepke JA. Home blood transfusions: the medical, economic, and legal issues surrounding a new treatment procedure. J Health Polit Policy Law 1988;13(3):565-79.

Kohrman AF. Psychological issues. In: Mehlman MJ, Younger SJ, ed. Delivering high technology home care. New York, NY: Springer Pub.; 1992: 160-78 [cited by Okun, 1995].

Kohrman AF. Chimeras and odysseys. Toward understanding the technologically dependant child. In: Arras JD, Porterfield WH, Porterfield LO, ed. Bringing the hospital home. Ethical and social implications of high-tech home care. Baltimore, MD: The Johns Hopkins University Press; 1995: 53-64.

Kraan RJ. Care for the elderly. Significant innovations in three European countries. Boulder, CO: Campus Westview; 1991.

Krause C. Easing the transition to high-tech home care. Caring 1994;13(2):5, 7, 51-2.

Krause C, Crowell P. Delegation: the new driving forces in the home care delivery system. Semin Nurse Manag 1995;3(4):185-90.

Laberge A, Aubin M, Vézina L, Bergeron R. La prestation de soins médicaux à domicile. Sondage dans la région de Québec. Can Fam Physician 2000;46:2022-9.

Lafaille R, Lebeer J. The relevance of life histories for understanding health and healing advances. J Mind Body Health 1991;7(4):16-31.

Lameire NH. Experience with CAPD as home dialysis. Int J Technol Assess Health Care 1985;1(2):305-13.

Lampron C, Martel A, Bergeron M, et al. L'implantation du programme d'antibiothérapie intraveineuse à domicile dans trois centres hospitaliers de la région socio-sanitaire de Québec. Sainte-Foy, QC: Laboratoire et service d'infectiologie, Centre de recherche, Centre hospitalier de l'Université Laval; 1991.

Larkin H. High-tech home care dilemma: physicians face payment struggle to get patients out of the hospital. AMA News, June 8, 1992. Chicago, IL: American Medical Association; 1992: 9 [cited by Arras et Dubler, 1995].

Larsen L. Home care in Canada: new challenges and opportunities. Proceedings of the Insight conference on community care: new opportunities to partner, September 18-19, 1996. Calgary, AB: Insight; 1996: 83-104.

Law J. Introduction: monsters, machines and sociotechnical relations. In: Law J, ed. A sociology of monsters. Essays on power, technology and domination. London, England: Routledge; 1991: 1-25.

Law S, Lehoux P. Hospital technology at home: report on home parenteral nutrition. Montréal: Agence d'évaluation des technologies et des modes d'intervention en santé; 2001 (unpublished).

Leat D. Caring for people who live at home: ways forward. In: Allen I, Cameron A, Perkins L, ed. Stimulating provision by the independent sector. Papers from the 1993 Caring for people who live at home conference. London, England: Policy studies institute; 1999: 20-4.

Leclerc BS. Enquête auprès des médecins de la région de Lanaudière au regard des impacts du virage ambulatoire et de la réorganisation des services de santé sur la pratique médicale et de la qualité des soins. Saint-Charles-Borromée, Qc: Régie régionale de la santé et des services sociaux Lanaudière; 1998.

Lehoux P, Pineault R, Richard L, St-Arnaud J, Law S, Rosenthal H. High-tech home care delivered by Quebec primary care organizations: are the sources of information about technology and relationships with hospitals of quality. Int J Health Care Qual Assur 2003;16(1):37-46.

Lehoux P, Charland C, Richard L, Pineault R, St-Arnaud J. Technologies de pointe et soins à domicile. Où en sont les CLSC? CMAJ 2002;166(10):1277-8.

Lehoux P, Charland C, Richard L, Pineault R, St-Arnaud J. Convivialité et cadre organisationnel des technologies utilisées à domicile. Rapport no. 1: Résultats de l'enquête par questionnaire auprès des gestionnaires des programmes de soins à domicile des CLSC. Montréal: GRIS; 2001a (R01-07).

Lehoux P, Charland C, Pineault R, Richard L, St-Arnaud J. Convivialité et cadre organisationnel des technologies utilisées à domicile. Rapport no. 2: Analyse des entretiens menés auprès de gestionnaires et de professionnels de soins à domicile en CLSC. Montréal: GRIS Université de Montréal; 2001b.

Lehoux P, Pineault R, Richard L, St-Arnaud J, Rosenthal H. Protocole de recherche. Convivialité et cadre organisationnel des technologies utilisées à domicile. Étude de cas. Ottawa: IRSC; 1998 (MA-15472).

Levy F, Doan BD. Les équipements technologiques nouveaux et leur impact économique en pratique médicale ambulatoire. Cah Sociol Demogr Med 1993;33(1):5-106.

Lindeman CA. Nursing & technology. Moving into the 21st century. Caring 1992;11(9):5, 7-10.

Lioté H, Comité d'évaluation et de diffusion des innovations technologiques. Télétransmission interhospitalière des paramètres polysomnographiques (syndrome d'apnées du sommeil). Paris, France: CEDIT; 1996.

Locas J, Ministère de la Santé et des Services Sociaux. Les services à domicile offerts par les CLSC au Québec. Analyse comparative des résultats des enquêtes 1988-89, 1990-91 et 1992-93. Québec: MSSS; 1995.

Loras Duclaux I, De Potter S, Pharaon I, Olives JP, Hermier M. Qualité de vie des enfants en nutrition parentérale à domicile et de leurs parents. Pédiatrie 1993;48(7-8):555-60.

Ludbrook A. The economics of home care for the treatment of end-stage renal failure. Int J Technol Assess Health Care 1985;1(2):315-24.

Lun KC. New user interfaces. Int J Biomed Comput 1995;39(1):147-50.

Lupton C, Hall B. Beyond the rhetoric: from policy to practice in user-involvement. Research, Policy and Practice 1993;10(2):6-11.

Lupton C, Taylor P. Involving consumers. Coming in from the cold. Health Serv J 1995;105(5444):22-4.

Lyon JC. Models of nursing care delivery and case management: clarification of terms. Nurs Econ 1993;11(3):163-78.

MacAdam M. Home care: it's time for a Canadian model. Healthc Pap 2000;1(4):9-36.

Martel AY, Lampron C, Gauthier J, Valois M, Joubert P, East L, Bergeron MG. Évaluation de l'introduction d'une innovation dans le domaine du traitement ambulatoire au Québec: le programme d'antibiothérapie intraveineuse à domicile (ATIVAD). Sainte-Foy, QC: CHUL, Laboratoire et service d'infectiologie, Centre de recherche; 1992: 2.

McCabe A, Paredes J, Pfister DG. Issues in long-term and high-tech home care for persons with HIV infection/AIDS. In: Arras JD, Porterfield WH, Porterfield LO, ed. Bringing the hospital home. Ethical and social implications of high-tech home care. Baltimore, MD: The Johns Hopkins University Press; 1995: 79-90.

McCoy K. The future through high-tech spectacles. Insight 1994;19(4):3, 7.

McNeal GJ. Telecommunication technologies in high-tech homecare. Crit Care Nurs Clin North Am 1998a;10(3):279-86.

McNeal GJ. Diversity issues in the homecare setting. Crit Care Nurs Clin North Am 1998b;10(3):357-68.

McNeal GJ. High-Tech home care: an expanding critical care frontier. Crit Care Nurse 1996;16(5):51-8.

Meade CD. Improving understanding of the informed consent process and document. Semin Oncol Nurs 1999;15(2):124-37.

Medical equipment service market changing in cost-conscious environment [editorial]. Health Technol Trends 1995;9(7):7-9.

Meurer LN, Meurer JR, Holloway R. New models of health care in the home and in the work site. Am Fam Physician 1997;56(2):384-6, 389.

Miller R, Lazar J. Public reporting of performance measures in home care. Jt Comm J Qual Improv 1995;21(3):105-15.

Milone-Nuzzo P. Home care in Changsha: a work in progress. Caring 1999;18(10):28-30, 32-3.

Ministère de l'industrie et du commerce du Québec (MIC). L'industrie du matériel médical au Québec. Québec: Les Publications du Québec; 1987.

Ministère de la Santé et des Services Sociaux (MSSS). Dépenses annuelles des provinces canadiennes pour le soutien à domicile 1999-2000. Tableau compilé à partir de données relevées auprès de représentants provinciaux. Québec: MSSS, Direction de la planification stratégique; 2001a.

Ministère de la Santé et des Services Sociaux (MSSS). Le système de santé et de services sociaux du Québec. Une image chiffrée. Québec: MSSS; 2001b.

Ministère de la Santé et des Services Sociaux (MSSS). Cadre normatif et protocole d'échange. Version 3: Système d'information sur la clientèle et les services des CLSC. Québec: MSSS; 1999.

Ministère de la Santé et des Services Sociaux (MSSS). Le virage ambulatoire en santé physique. Enjeux et perspectives. Québec: MSSS, Direction générale de la planification et de l'évaluation; 1998.

Ministère de la Santé et des Services Sociaux (MSSS). Portrait de la transformation du système de santé et de services sociaux du Québec. Québec: Les Publications du Québec; 1997.

Ministère de la Santé et des Services Sociaux (MSSS). Statistiques évolutives des dépenses gouvernementales pour la mission sociale 1986-1987 à 1995-96. Québec: MSSS, Direction générale de la planification et de l'évaluation; 1996.

Ministère de la Santé et des Services Sociaux (MSSS). Programme de virage ambulatoire [editorial]. Volet : santé physique. Entente cadre entre le CHRDL et les CLSC du nord de Lanaudière. Québec: MSSS; 1995.

Ministère de la Santé et des Services Sociaux (MSSS), Association des néphrologues du Québec. Gestion et suivi de la dialyse rénale. Québec: MSSS; 1995a.

Ministère de la Santé et des Services Sociaux (MSSS), Association des néphrologues du Québec. Problèmes de vie et distribution géographique des personnes dialysées. Résultats de l'enquête 1992-93. Québec: MSSS; 1995b.

Ministère de la Santé et des Services Sociaux (MSSS), Association des néphrologues du Québec. La dialyse et son organisation. Québec: MSSS; 1995c.

Ministère de la Santé et des Services Sociaux (MSSS), Groupe d'experts en organisation clinique. La réalisation du virage ambulatoire par les CLSC de la région de Laval. Montréal: MSSS; 1998c.

Miyaji NT. The power of compassion: truth-telling among American doctors in the care of dying patients. Soc Sci Med 1993;36(3):249-64.

Monette P. Borrowed time: an AIDS memoir. New York, NY: Avon Books; 1988 [cited by Arras and Dubler, 1995].

Monk A, Cox C. Trends and developments in home care services: an international perspective. In: Kaye LW, ed. New developments in home care services for the elderly: innovations in policy, program, and practice. New York, NY: The Haworth Press; 1995: 251-70.

Montreal Children Hospital, McGill University Health Center, Bélanger G, Farrougia C. Annual report 1998-1999. Intensive ambulatory care service. Montréal: The Montreal Children Hospital, McGill University Health Center; 1999.

Mor V, Rice C. Physician use among patients receiving cancer chemotherapy. Cancer 1993;71(1):219-25.

Moxley JHI, Roeder PC. How trends will interact: the perspective of the hospital. In: Ekelman KB, ed. New medical devices. Invention, development, and use. Washington, DC: National Academy Press; 1988: 127-37.

Nadash P. Delegation. Creating a balance among home care, the disability community, regulators, and payors. Caring 1998;17(7):20-1, 23, 25.

Namiash D, Reis M, Health Canada. Community Health Division. An exploratory study of private home care services in Canada. Ottawa : Community Health Division, Health and Welfare Canada; 1992.

National Association for Home Care. Basic statistics about home care. Washington, DC: NAHC; 1994 [cited by Kaye, 1995].

Neuberger J. Patient's rights: A middle class phenomenon? In: Griffin J, ed. Health information and the consumer. London, England: Office of Health Economics; 1995: 66-73.

Newell M. Transitioning the critical care nurse from ICU to high-tech homecare. Crit Care Nurs Clin North Am 1998;10(3):259-66.

Noddings N. Moral obligation or moral support for high-tech home care? Hastings Cent Rep 1994;24(5):S6-10.

Norman LA, Hardin PA, Lester E, Stinton S, Vincent EC. Computer-assisted quality improvement in an ambulatory care setting: a follow-up report. Jt Comm J Qual Improv 1995;21(3):116-31.

Okun A. The history of respirators and total parenteral nutrition in the home and their use in children today. In: Arras JD, Porterfield HW, Porterfield LO, ed. Bringing the hospital home. Ethical and social implications of high-tech home care. Baltimore, MD: The Johns Hopkins University Press; 1995: 35-52.

O'Malley AS, Forrest CB. Continuity of care and delivery of ambulatory services to children in community health clinics. J Community Health 1996;21(3):159-73.

O'Sullivan MJ, Volicer B. Factors associated with achievement of goals for home health care. Home Health Care Serv Q 1997;16(3):21-34.

Ordre des infirmières et infirmiers du Québec. Perspectives des soins infirmiers dans le contexte du virage ambulatoire. Répertoire d'initiatives. 2nd ed. Montréal: OIIQ; 1996.

Palakkamanil T. Ambulatory care north of 60 degrees north latitude. J Ambul Care Manage 1993;16(3):56-60.

Parent K, Anderson M, Canadian Association of Retired Persons. Home care by default not by design. CARP's report card on home care in Canada 2001. Kingston, ON: Queen's Health Policy Research Unit, Queen's University; 2001.

Parent K, Anderson M. Developing a home care system by design. Healthc Pap 2000;1(4):46-52, 109-12.

Parkes J, Shepperd S. Discharge planning from hospital to home. Cochrane Database Syst Rev 2000;(4):CD000313.

Perkins E, Allen I, Dowling S, Leat D. Creating partnerships in social care. An evaluation of the caring people at home initiative. London, England: Policy studies institute; 1997.

Perneger TV, Stalder H, Schaller P, Raetzo MA, Etter JF. Satisfaction des patients en milieu ambulatoire: validation d'une échelle et identification de facteurs associés. Schweiz Med Wochenschr 1996;126(20):864-71.

Perry S, Chu F. A conflict: medical innovation, access and cost containment. In: Ekelman K, ed. New medical devices. Invention, development, and use. Washington, DC: National Academy Press; 1988: 104-26.

Petit de Mange EA. Pediatric considerations in homecare. Crit Care Nurs Clin North Am 1998;10(3):339-46.

Petty TL. Lungs at home. Monaldi Arch Chest Dis 1996;51(1):60-3.

Petty TL. Home oxygen therapy. Mayo Clin Proc 1987;62(9):841-7.

Petty TL, O'Donohue WJ. Further recommendations for prescribing, reimbursement, technology development, and research in long-term oxygen therapy. Summary of the Fourth Oxygen Consensus Conference, Washington, DC, October 15-16, 1993. Am J Respir Crit Care Med 1994;150(3):875-7.

Pfister D. Oncology and high-tech home care. In: Arras JD, Porterfield WH, Porterfield LO, ed. Bringing the hospital home. Ethical and social implications of high-tech home care. Baltimore, MD: The Johns Hopkins University Press; 1995: 65-79.

Pilling M, Walley T. Contracting for high-tech health care for patients at home: a survey of purchaser responses. J Manag Med 1996a;10(6):17-23, 2.

Pilling M, Walley T. Effective contracting of high-tech health care for patients at home. J Manag Med 1996b;10(3):6-14.

Pippin K, Fernie GR. Designing devices that are acceptable to the frail elderly: a new understanding based upon how older people perceive a walker. Technol Disabil 1997;7:93-102.

Poretz DM. Infusion center, office, and home. Hosp Pract 1993;28(Suppl 2):40-62.

Pousada L. High-tech home care for elderly persons. What, why and how much? In: Arras JD, Porterfield WH, Porterfield LO, ed. Bringing the hospital home. Ethical and social implications of high-tech home care. Baltimore, MD: The Johns Hopkins University Press; 1995: 107-27.

Prout A, Hayes L, Gelder L. Medicines and the maintenance of ordinariness in the household management of childhood asthma. Sociol Health and Illn 1999;21(2):137-62.

Richards A, Carley J, Jenkins-Clarke S, Richards DA. Skill mix between nurses and doctors working in primary care-delegation or allocation: a review of the literature. Int J Nurs Stud 2000;37(3):185-97.

Rodriguez R, Frohlich KL. The role of community organizations in the transformation of the health services delivery system in the Montreal metropolitan area. Can J Public Health 1999;90(1):41-4.

Rogers DW, Jobes HM, Hinshaw JR, Lanzafame RJ. Ergonomics of medical lasers: operator's viewpoint. J Clin Laser Med Surg 1992;10(3):199-206.

Romanow R. Building on values: the future of health care in Canada. Ottawa: Commission on the future of health care in Canada; 2002.

Romeo AA. Private investment in medical device innovation. In: Ekelman KB, ed. New medical devices. Invention, development, and use. Washington, DC: National Academy Press; 1988: 62-72 .

Rosenfeld M, Emerson J, Astley S, Joy P, Williams-Warren J, Standaert TA, et al. Home nebulizer use among patients with cystic fibrosis. J Pediatr 1998;132(1):125-31.

Rosenzweig EP. Trends in home care entitlements and benefits. In: Kaye LW, ed. New developments in home care services for the elderly: innovations in policy, program, and practice. New York, NY: The Haworth Press; 1995: 9-30.

Rosser WW. Approach to diagnosis by primary care clinicians and specialists: is there a difference? J Fam Pract 1996;42(2):139-44.

Ruddick W. Transforming homes and hospitals. In: Arras JD, Porterfield WH, Porterfield LO, ed. Bringing the hospital home. Ethical and social implications of high-tech home care. Baltimore, MD: The Johns Hopkins University Press; 1995: 166-79.

Saint-Arnaud J. Enjeux éthiques et technologiques biomédicales. Montréal: Presses de l'Université de Montréal; 1999.

Salazar WH. Management of depression in the outpatient office. Med Clin North Am 1996;80(2):431-55.

Sawyers JE. Defining your role in ambulatory care: clinical nurse specialist or nurse practitioner? Clin Nurse Spec 1993;7(1):4-7.

Scales K. Legal and professional aspects of intravenous therapy (continuing education credit). Nurs Stand 1996;11(3):41-6.

Scales K. Practical and professional aspects of i.v. therapy. Prof Nurse 1997;12(Suppl 8):S3-5 [cited by Campbell et Lunn, 1997].

Schachter SR, Holland JC. Psychological, social, and ethical issues in home care of terminally ill patients: the impact of technology. In: Arras JD, Porterfield WH, Porterfield LO, ed. Bringing the hospital home. Ethical and social implications of high-tech home care. Baltimore, MD: The Johns Hopkins University Press; 1995: 91-106.

Secor, Comité du bilan de l'activité scientifique et technologique de la région de Montréal, Conseil de la science et de la technologie. L'industrie des technologies médicales: bilan de l'activité scientifique et technologique de la région de Montréal. Sainte-Foy, QC: Conseil de la science et de la technologie; 1992.

Sharkey S. The changing face of community care. Proceedings of the Insight conference on community care: new opportunities to partner, September 18-19, 1996. Calgary: Insight; 1996: 83-104.

Short LA, Saindon EH. Telehomecare rewards and risks. Caring 1998;17(10):36-40, 42.

Sloan JP, Buchanan B. Performance of the "house doctor". Effect of physician-to-patient ratio on follow up in long-term care facilities. Can Fam Physician 1993;39:273-6.

Smith HL, Hood JN, Piland NF. Leadership and quality of working life in home health care. Home Health Care Serv Q 1994;14(4):3-22.

Soderstrom L, Tousignant P, Kaufman T. The health and cost effects of substituting home care for inpatient acute care: a review of the evidence. CMAJ 1999;160(8):1151-5.

Sorochan MW. International models. Home care in Canada. Caring 1995;14(1):12-9.

Stavins CL. Ambulatory nursing: facing the future. J Ambul Care Manage 1993;16(4):67-71.

Stearns JA, Glasser M. How ambulatory care is different: a paradigm for teaching and practice. Med Educ 1993;27(1):35-40.

Strauss A, Fagerhaugh S, Suczek B, Wiener C. Social organization of medical work. Chicago, IL: University of Chicago Press; 1985.

Strauss MB, Hart JD, Winant DM. Preventive foot care. A user-friendly system for patients and physicians. Postgrad Med 1998;103(5):233-6, 239-40, 245.

Sudia-Robinson TM. Neonatal intensive care in the home. Home Care Provid 1998;3(6):290-2.

Suther M. "High-tech" home care at the VNA of Texas. Caring 1999;18(8):6-8.

Tang PC, Jaworski MA, Fellender CA, et al. Methods for assessing information needs of clinicians in ambulatory care. In: Annual Symposium on computer applications in medical care. Proceedings 1995. Bethesda, MD: American Medical Informatics Association; 1996: 630-4.

Thier SO. New medical devices and health care. In: Ekelman KB, ed. New medical devices. Invention, development, and use. Washington, DC: National Academy Press; 1988: 3-12.

Thomas S. Computerization in clinical laboratories and health care facilities: making decisions in transition. Part II: Understanding user friendliness, computer assisted physician ordering, patient informational needs. Can J Med Technol 1994;56(3):178-81.

Thompson LG. Clear goals, solid evidence, integrated systems, realistic roles. Healthc Pap 2000;1(4):60-6, 109-12.

Trahan L, Demers M, Ministère de la Santé et des Services Sociaux (MSSS). Rétention et auto-suffisance des régions en matière de services médicaux ambulatoires et d'hospitalisation. Québec: MSSS, Direction générale de la planification et de l'évaluation; 1998 [cited by Béland et Bergman, 2000].

Tunissen C, Knapen M. The national context of social innovation. The Netherlands. In : Kraan RJ. Care for the elderly. Significant innovations in three European countries. Boulder, CO: Campus Westview; 1991: 7-27.

van den Boom F. AIDS in the family: a personal reflection. AIDS Patient Care 1991;273-9 [cited by Arras et Dubler, 1995].

van Raak A, Mur-Veeman I. Home care policy in the Netherlands. Reforming legislation to facilitate the provision of multi-disciplinary home care. Health Policy 1996;36(1):37-51.

Verhey MP. Quality management in home care: models for today's practice. Home Care Provid 1996;1(4):180-8, 211.

Verry AM. Safety in home care of the frail elderly: dilemmas and trade-offs. Would you take this patient home? J Long Term Home Health Care 1997;16(4):20-3.

Wadhwa S, Lavizzo-Mourey R. Tools, methods, and strategies. Do innovative models of health care delivery improve quality of care for selected vulnerable populations? A systematic review. Jt Comm J Qual Improv 1999;25(8):408-33.

Watrous J, Zappia P. Application of the FOCUS-PDCA model to home care equipment management. Am J Med Qual 1993;8(2):94-6.

Watzke JR. Older adults' responses to an automated integrated environmental control device: the case of the remote gateway. Technol Disabil 1997;7:103-14.

Weissert WG. Seven reasons why it is so difficult to make community-based long-term care cost-effective. Health Serv Res 1985;20(4):423-33 [cited by Thompson, 2000].

Weissert WG, Lesnick T, Musliner M, Foley KA. Cost savings from home and community-based services: Arizona's capitated Medicaid long-term care program. J Health Polit Policy Law 1997;22(6):1329-57 [cited by Thompson, 2000].

Wesdock M. Pediatric high-tech home care: a growing alternative. Nurs Spectr (Washington, DC) 1996;6(13):6.

Whitehead EC, Kahn AR, Safir A, Greatbatch W, Hotchkiss R. Inventing medical devices: five inventors' stories. In: Ekelman KB, ed. New medical devices. Invention, development, and use. Washington, DC: National Academy press; 1988: 13-34.

Wiklund ME. AAMI's influence on the design of user-friendly medical devices. Biomed Instrum Technol 1995;29(3):229-31.

The Wilkerson Group. Forces reshaping the performance and contribution of the US medical device industry. Report prepared for the Health Industry Manufacturers Association. Washington, DC: The Wilkerson Group; 1995.

Wilkinson R. Nurse's concerns about IV therapy and devices. Nurs Stand 1996;10(35):35-7 [cited by Campbell et Lunn, 1997].

Williamson A. Concluding remarks. In: Allen I, Cameron A, Perkins L. Stimulating provision by the independent sector. London, England: Policy studies institute; 1999: 68-71.

Wilson J. Two worlds. Selfhelp groups and professionals. Report prepared for the British Association of Social Workers. Birmingham, England: British Association of Social Workers; 1996.

Worcester MI. Tailoring teaching to the elderly in home care. Washington, DC/: University of Washington, Institute on aging; 1987 [cited by Kaye et Davitt, 1995].

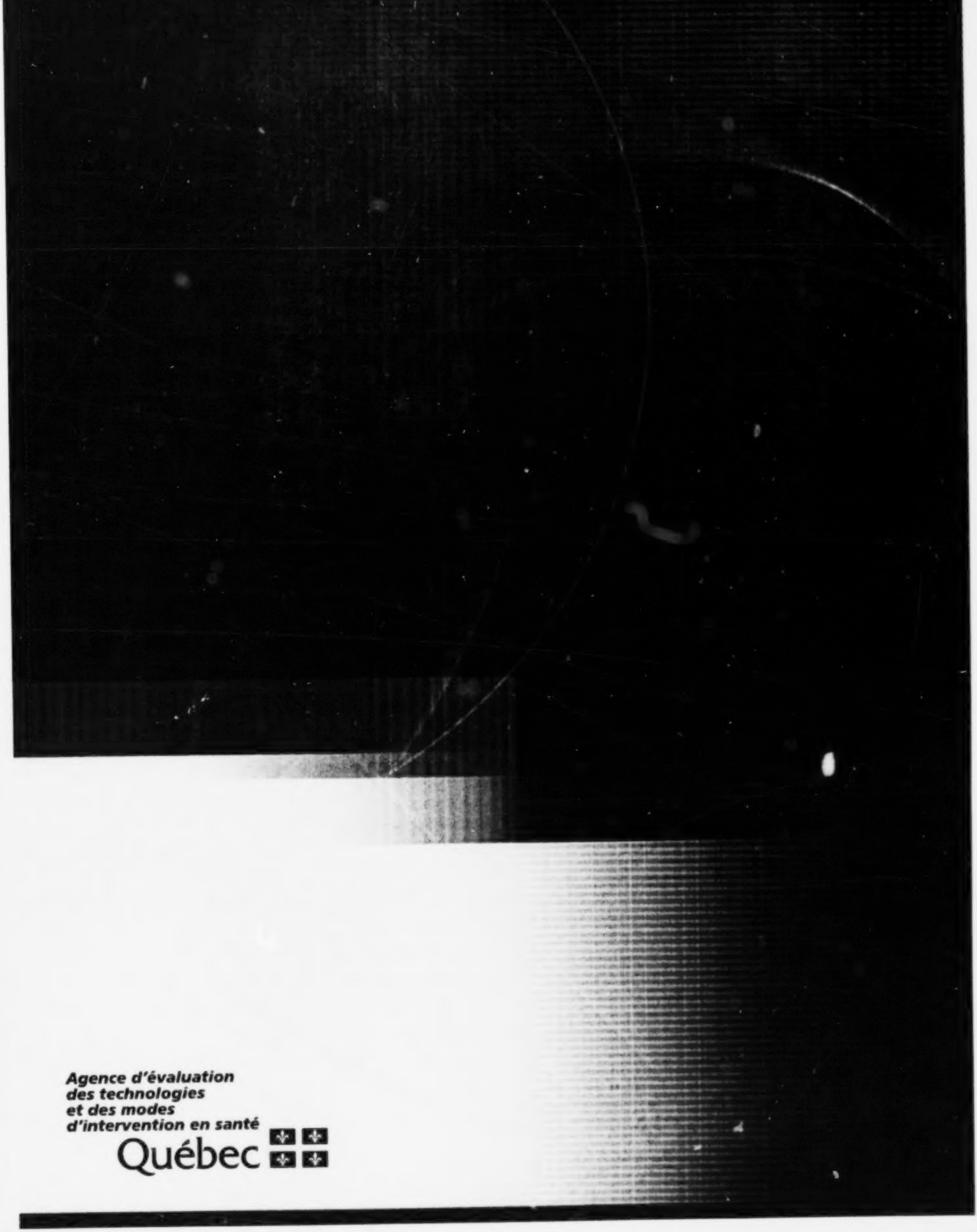
Yager D. "The Reading Assistant": user-friendly technology for the visually impaired. Optom Vis Sci 1995;72(5):343-5.

Zarbock SF. ET, phone home: telehome care. Home Care Provid 1998;3(5):249-50.

Zarbock SF. Home medical equipment suppliers: a critical home care partner. Home Care Provid 1997;2(1):112-4.

Zarbock SF. More than squeaky blue shoes and a black bag. Home care in a rural area. Home Care Provid 1996;1(4):205-6.

Zerwekh JV. High-tech home care for nurses: questioning technologies. Home Healthc Nurse 1995;13(1):9-16.



**Agence d'évaluation
des technologies
et des modes
d'intervention en santé**

Québec